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A SYSTEMATIC APPROACH TO DEVELOPING AN INDIVIDUALIZED FAMILY SERVICE PLAN: A PILOT PROJECT

BY

CATHY ANNE MARTIN ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements of the degree of Master of Education.

IN

SPECIAL EDUCATION (SEVERE DISABILITIES)
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA
FALL, 1993

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ISBN 0-315-88433-9

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DEGREE: MASTER OF EDUCATION

YEAR DEGREE GRANTED: 1993

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled A SYSTEMATIC APPROACH TO DEVELOPING AN INDIVIDUALIZED FAMILY SERVICE PLAN: A PILOT PROJECT submitted by Cathy Anne Martin in partial fulfilment of the requirements for the degree of Master of Education in the Severe Disabilities Program.

Dr. Gerard Kysela

Dr. Linda McDonald

N Keating

Dr. Nora Keating

September, 1993

DEDICATION

This thesis is dedicated to the many families I have had the privilege of working with throughout this project and throughout my career. Their commitment, energy, love and compassion for children is nothing less than heroic. These families have inspired me to work together with people from all disciplines to meet the needs of their children. It is through the dedication of these parents, and those whom they influence, that our youngest citizens become educated and valued as integral members of society, now and in the future.

ABSTRACT

The purpose of this study was to evaluate the practicality of a model and a process that could be used by parents and professionals to incorporate assessment data directly into individualized family service plans (IFSPs). The participants in this study were parents of preschool children with developmental disabilities who were receiving some services from a community preventative health care agency and/or early childhood special education program. The four families who completed the final questionnaire live in two rural communities in Alberta.

The intervention consisted of a series of home visits to these families over a four month period. Data from some of the assessments completed by these parents in a previous study (Redington, 1992) were presented to the research participants and they were invited to use these data to develop an IFSP for their family. Evaluation of this process was done by asking participants to once again complete the measures used in the Redington study, and to fill out an informal questionnaire.

Guidelines for enabling and empowering parents to better meet their own

needs and those of their child with disabilities were employed throughout the course of this study. The literature supports this practical application of family assessment results and highlights the trend towards family members taking more of a leadership role in the delivery of services to their family system. Research participants found that the assessment information did accurately reflect their family's strengths and needs, but had varying opinions regarding the practicality of the formal assessments and the development of an IFSP.

ACKNOWLEDGEMENTS

This project would not have been possible without the great deal of support I received from my co-workers, friends and thesis advisors. I would like to thank Dr. McDonald and Dr. Kysela for their assistance, insight and encouragement in this project. Their work with, research of and dedication to families of children with special needs has been a great source of inspiration to me and it has been a privilege to work so closely with them. My friend and editor, Allison, deserves a great deal of thanks for her patience and tolerance of my seclusion and occasional episodes of panic when deadlines were pending. To my co-workers and supervisor, I wish to express my sincere appreciation for their support and understanding of my erratic schedules over the past four years. These professionals have been my role models for compassion and excellence as they work with children who have special needs and their families.

TABLE OF CONTENTS

CHAPTER PAGE

CHAPTER I - INTRODUCTION.. 1

Purpose of the Study.. 5

Operational Definitions.. 7

CHAPTER II - REVIEW OF THE LITERATURE................. 9

Overview.. 9

Family Systems Theory.. 11

The T-Double ABCX Model...................................... 15

The Family Focussed Approach................................. 18

Models of Parental Partnership and Interagency Collaboration 21

Assessing the Strengths and needs of Families................ 26

Assessments, Stress and Family Functioning.................. 32

Individualized Family Service Plans............................. 34

Summary... 36

CHAPTER PAGE

CHAPTER III - METHODS AND PROCEDURES.................. 37

Describing and Measuring the Pile-Up of Stressors.......... 39

Describing and Measuring Family Resources................. 41

Describing and Measuring Family Perceptions of Crisis.... 43

Describing and Measuring Family Problem Solving/Coping 45

Describing and Measuring Family Adaptation................ 47

Research Questions.. 48

Description of Participants...................................... 51

Procedures.. 54

Data Collection.. 58

Data Analysis.. 59

Confidentiality... 61

Conclusion.. 62

CHAPTER PAGE

CHAPTER IV - RESULTS.. 63

Summary of Visits.. 63

Answers to Research Questions.. 70

Conclusion.. 83

CHAPTER V - DISCUSSION.. 84

Interpretation of the Results.. 84

Limitations of the Study.. 91

Recommendations for Future Research.. 93

Applying the IFSP Process in Local Programs.. 93

Conclusion.. 97

REFERENCE LIST.. 98

CHAPTER PAGE

APPENDIX A - Final Questionnaire.................................... 107

APPENDIX B - Protocol for Home Visits.............................. 112

APPENDIX C - Overview of Proposal for Cooperating Agency... 120

APPENDIX D - Consent Form and Letter of Introduction.......... 125

APPENDIX E - Family Profile and Summary Sheets................ 128

APPENDIX F - Glossary of Terms...................................... 135

APPENDIX G - IFSP Form.. 142

APPENDIX H - Summary of Responses to Final Questionnaire... 146

APPENDIX I - Proposed Revised IFSP Form......................... 148

LIST OF TABLES

TABLE PAGE

1. Summary of Assessment Measures.............................. 17

2. Reliability and Validity Measures for Assessment Instruments 38

3. Comparison of Normed Samples, Pre and Post Test Scores 60

CHAPTER I - INTRODUCTION

Educational programs for preschool children with special needs have been in existence for over 20 years (LeLaurin & Wolery, 1992). Early preschool programs were based on a medical model that focussed attention only on the child with special needs and viewed the parents as providers of their child's therapy (Bazyk, 1989; Winton, 1986), or as pathologically needy hindrances to their child's growth and development (Freeman, 1989). The aim of these programs was to remediate deficits in the child's development as indicated by goals written in Individualized Educational Plans (IEPs). The goals in the IEPs were set for children mainly by professionals (Vincent, 1989), with parents basically rubber-stamping their approval on the program for their child (Leyser & Brobst-Cole, 1987). There was little opportunity for parents to have real input in the development of these goals, let alone have their own needs, strengths, priorities and philosophies considered as relevant factors in their child's growth and learning (Allen & Stefanowski-Hudd, 1987).

More recently, two emerging factors have created the need for a document that includes the strengths and needs of family members, as well as those of the child with disabilities when setting educational goals. Public laws in the United States and the overall trend to include all family members in the development and implementation of program goals, have been catalysts for interventionists to incorporate a family focussed approach to improving the development of children with special needs (Able-Boone, 1993). The Individualized Family Service Plan (IFSP) is a document that is well suited to this purpose , although its implementation has been considered inconsistent and even controversial (Goodman & Hover, 1992; Raver & Kilgo, 1991; Williams-Brown, 1991; Wyngaarden-Krauss, 1990) throughout the field of preschool special education.

Children with special needs and their families have long been exposed to a wide variety of assessments that attempt to identify the strengths and needs of all family members. These assessments have been used as pre and post tests to evaluate various types of interventions (McClellan, 1990) and as information sources prior to the development of Individualized Family Service Plans (IFSP's) (Bailey & Simeonsson, 1988; Deardorff, 1992; Olson & Kwiatkowski, 1992). Identifying the needs and strengths of the family members has become an important step in the development of an IFSP (Beckman & Bristol, 1991; Olson & Kwiatkowski, 1992). Dunst, Trivette, and Deal (1988) stated that assessment measures help family members identify the issues and activities towards which they wish to direct most of their time and energy.

The development of goals and intervention strategies should be directly linked to information gathered from assessment measures (Slentz & Bricker, 1992) and therefore it is important that these measures accurately reflect the needs and resources of the family system as they are perceived by its members (Bailey & Blasco, 1990). Family members need many opportunities to confirm, refute or revise the information identified in the assessment measures (Bailey & Simeonsson, 1988). Information gathered through these assessments has not generally been presented back to the parents in a way that would enable them to take a leadership role in accessing and implementing the services and programs that will benefit the family system (Bailey, Dunst, Kramer, Turnbull, Hurth, & Brown, 1989). The practice of not fully disclosing assessment information has led to criticism in the literature about the appropriateness of formal assessment measures for families of children with disabilities (Goodman & Hover, 1992; Slentz & Bricker, 1992).

Some of the issues involved with the successful implementation of an IFSP are related to the complex dynamics of a family of a child with disabilities (Beckman & Bristol, 1991). The problems and resources facing families with a member who has special needs are multidimensional (Friedrich, Greenberg, & Crnic, 1983) and therefore require an intricate framework in which interventionists can organize the assessment information. The T-Double ABCX model of family adaptation (McCubbin & Patterson, 1981) provides a useful outline for organizing this type of data. This model views the family as a dynamic system and identifies ways in which the family system may respond to change (crisis) over time. The model is able to achieve this by addressing such components as stressors, family resources, definition of the event and adaptation of the family system (McCubbin & Patterson, 1981; Orr, Cameron, & Day, 1991). It has been suggested that the T-Double ABCX model may be used as a common framework to facilitate comparison among studies on family functioning (Minnes, McShane, Forkes, Green, Clement, & Card, 1989).

A recent study (Redington, 1992) has compiled information from families in rural Alberta using the T-Double ABCX framework and family systems theory. The information gathered in the Redington study consists of parents' responses to a battery of family stress, coping and resource measures that correspond to the various dimensions of the T-Double ABCX model. The Redington study demonstrated that the T-Double ABCX model was useful as a tool when integrating research and clinical practice with families of children with special needs.

Purpose of the Study

There remain a number of issues surrounding the use of IFSPs with families of children with special needs. These issues include the intrusiveness of assessment measures (Slentz & Bricker, 1992), the usefulness of assessment measures as perceived by parents (Sexton, Snyder, Rheams, Barron-Sharp, & Perez, 1991), the effectiveness of various models of collaborating with family members (Goodman & Hover, 1992) and the legal, structural and fiscal barriers to successful implementation of IFSPs (Williams-Brown, 1991). The absence of Canadian research on the development of IFSPs highlights the need for study of this topic based on the requirements and recommendations of local families without the boundaries imposed by legislation.

The purpose of this study was to introduce and evaluate an IFSP process that assisted parents in transforming data from stress and coping measures completed in the Redington study into a functional plan created, directed and implemented by members of the family system. This study piloted a process of creating an IFSP by presenting parents with information obtained from assessment measures and invited them to use this information to identify strengths, needs and goals that would be helpful for their entire family system. The families were visited approximately once a month for 4 months. The principles of family focussed intervention as outlined by Bailey and Simeonsson (1988) and Dunst et al. (1988) were incorporated at each visit with the research participants.

The Literature Review describes the many issues and components involved in creating comprehensive IFSPs for families of children with special needs. The specific characteristics of the measures used to evaluate the IFSP process are outlined in the Methods and Procedures chapter. This chapter also includes an overview of the research design and questions that guided the study. A summary of information contained on the final assessment measures and questionnaires, and a description of the individual home visits are revealed in

Chapter IV (Results). The limitations of the study and possible implications for future research and clinical application of the IFSP process are detailed in the final Discussion chapter of this thesis.

Operational Definitions

For the purpose of this project, the term **interventionist** refers to a professional who interacts with family members to help promote the skill level of the child with disabilities and the overall well-being of the family system.

Empowerment has been defined as "the ability of families to manage life events effectively, as well as gain mastery over their affairs" (Dunst et al., 1988, p. 6). This concept of empowerment has been the foundation for this research project.

The goals of **family focussed intervention** have been described by Bailey and Simeonsson (1988) as:

1) To help family members cope with the unique needs related to caring for and raising a child with a handicap.

2) To help family members grow in their understanding of the development of their child both as an individual and as a family member.

3) To promote parent/child interactions which are; warm, mutually enjoyable and appropriately stimulating at the child's developmental level.

4) To preserve and reinforce the dignity of families by respecting and responding to their desire for services and incorporating them in the assessment, planning and evaluation process. (pp.18-19).

These goals were an integral part of every contact with the families who participated in this study.

CHAPTER II - REVIEW OF THE LITERATURE

This study incorporates a variety of frameworks, theories and practices in order to develop effective IFSP documents for families of children with special needs. Family systems theory and the T-Double ABCX model of family adaptation provide the framework around which assessment information is organized. The principles associated with family focussed intervention and creating partnerships among parents and professionals are identified and incorporated into the processes used to create IFSPs. Finally, the issues involved with assessing family needs and developing effective IFSPs are discussed and evaluated. The best practices associated with all of the components mentioned above are identified and used as guiding principles for the procedures implemented in this study.

Overview

There is an abundance of literature regarding ways to assess the stress levels and coping mechanisms of families with a member who has special needs (Dunst et al., 1988; Dyson, 1991; Frey, Greenberg, & Fewell, 1989; Hanson & Hanline, 1990; Zeitlin, Williamson, & Rosenblatt, 1987). These studies have provided us with a great deal of insight into some of the primary stressors in these family systems (Hanson & Hanline, 1990) and information on the practical ways that families have managed the various challenges involved with living with a child with special needs (Minnes et al., 1989; Orr et al., 1991). Identifying and recording the needs and resources of families however, is only a small part of family focussed intervention. This list must be translated into functional plans for the learning and development of the child and strengthening of the family system (Bailey, 1987). Despite the vast amount of research expressing the need for this translation, there seems to be little written on ways to directly turn the information from assessment measures, indexes and surveys into effective program and service delivery plans for children with disabilities and their family members.

Research that strives to develop helpful ways of supporting families of children with disabilities may be more effective if it employs frameworks which incorporate the many dimensions involved in the process of family adaptation (Orr, et al. 1991). Family systems theory has been used in conjunction with the T-Double ABCX model of family adaptation to help researchers and interventionists better understand the processes parents experience when they have a child with disabilities (Bristol, 1987; Deardorff, 1992; McCubbin & Patterson, 1981). When these two frameworks are combined with the principles of the family focussed method of service delivery, useful interventions can develop that strengthen the integrity of the family system (Bailey & Simeonsson, 1988; Bernheimer, Gallimore, & Weisner, 1990; Deal, Dunst, & Trivette, 1989; Olson & Kwiatkowski, 1992). The importance of using these well established frameworks when organizing information and responding to the needs of children with disabilities and their families has been extensively documented in the literature (e.g. Dunst et al., 1988; Olson & Kwiatkowski, 1992; Redington 1992; Winton, 1986).

Family Systems Theory

Family systems theory provides a well established framework from which to view family functioning and interaction patterns (Bailey, 1987). This theory views the family as a system that has its own structure, boundaries, and is organized primarily to maintain stability within the system (Bailey, 1987; Berdie & Selig, 1981; McCubbin & Patterson, 1981; Redington, 1992). It also provides a model for viewing the family in relation to other structures such as the political, economic, medical, educational and legal systems that exist in society (Dunst et al., 1988).

As parts of a unified system, family members are constantly interacting with and affecting the activities and belief systems of one another (Benson & Turnbull, 1988; Berdie & Selig, 1981). A change in one part of the system will inevitably lead to changes in other parts of the family system (Bailey & Simeonsson, 1988; Montgomery, 1982; Olson & Kwiatkowski, 1992). Goldenberg and Goldenberg (1980) describe the interrelationship among elements of a family system as forming a new "whole" entity that is larger than the sum of the individual parts. The interconnectedness of the system parts is a central component of family systems theory and has been the primary rationale for providing support to all family members when educating young children with special needs. Family systems theory has shown to enhance the level of satisfaction among parents when used as a framework to develop IFSPs. Caro and Derevensky (1991) stated that parents had a positive view of the IFSP process when the needs of the entire family were included in the document.

Boundaries are the rules that define membership within the family system (Olson & Kwiatkowski, 1992) and serve the function of separating the family from the societal and natural (biological) systems that exist in the environment (Deacon & Firebaugh, 1981). The flow of information in and out of the family system is controlled through the permeability of its boundaries. Impermeable boundaries are characteristic of virtually closed systems. Families with impermeable boundaries have difficulty accepting new people into their family, hold tight to family traditions and beliefs, and do not respond quickly to new ideas or information. Open systems more freely accept influences from outside sources and readily include friends and support workers into the family through permeable boundaries (Aldous, 1978). The permeability of boundaries lies on a continuum from highly permeable, which may lead to systems that have no identity; to extremely impermeable, where family members may become out of touch with information and influence from other systems (Olson & Kwiatkowski, 1992).

A primary function of a system is to maintain balance, stability and consistency (homeostasis) within its boundaries (Berdie & Selig, 1981; Olson & Kwiatkowski, 1992). When a change (stressor) is introduced to a family system, the members strive to create a situation similar to the way it was before the stressor event occurred (Montgomery, 1982). Homeostasis provides a sense of predictability and security for the system. It is important for interventionists to recognize and support the strategies that family members use to rebuild a sense of order and balance in their lives (Schultz, 1984). By identifying these strategies, interventionists can better understand the potential reluctance of the family system to quickly adapt to the challenges of a child with special needs (Olson & Kwiatkowski, 1992).

Family systems theory is helpful when assessing the needs and strengths of a family with a member who has special needs. It helps researchers and interventionists more fully comprehend the complexity of the interactions that these families accommodate as they strive to provide the best program possible for the child with disabilities and her/his family. The family systems model also displays the strong relationship between the needs and resources of parents and the well-being of their children (Mahoney, O'Sullivan, & Dennebaum, 1990). Beatty (1993) states that the status of the child and family are inextricably intertwined. Perhaps the child centred focus of early preschool programs was not as effective as it could have been due to its failure to see the child as part of a larger family system (Seligman & Benjamin-Darling, 1989).

The T-Double ABCX Model of Family Adaptation

The T-Double ABCX model (McCubbin & Patterson, 1981) is useful in organizing comprehensive assessment data since it incorporates dimensions of time, resources, perceptions and adaptation strategies all within one dynamic framework (Deardorff, 1992). This model is based on Hill's (1949) original work that organized aspects of coping in families separated, then reunited during the second world war. His single abcx model looked at the components of stressors ("a"), existing resources ("b"), and the perception or definition of the stressor ("c"). These three variables influenced the system's ability to maintain stability, and prevent a change within the family from creating a crisis situation ("x") (McCubbin & Patterson, 1981).

McCubbin & Patterson (1981) expanded upon Hill's (1949) model to incorporate the dimension of the "pile up" of stressors that could occur over time. Their newer model extends past the original crisis (x), to the "aA" factor (the pile up of stressors). They label existing and new resources of the family system as the "bB". The "cC" factor incorporates the family members' *perceptions* of the original crisis (x), the pile up of stressors ("aA") and the resources of the system ("bB" factor). A fourth component of this theory involves the coping strategies family members employ to deal with the stressors imposed upon the system ("PSC" factor). These four factors interact to lead the system into the adaptation ("xX") phase of the model. Adaptation could take the form of "bonadaptation" which implies that stability of the system has been maintained, or "maladaptation" which indicates that the system is in a state of imbalance.

Redington (1992) evaluated the utility of the T-Double ABCX model by gathering information from parents through assessment measures that corresponded to the various dimensions of the model (see Table 1). The Redington (1992) study showed that there is a relationship between the needs identified by parents, and needs inferred from the various aspects of the model. Results from this study seemed to indicate that the T-Double ABCX framework provided a useful tool for integrating research and practice.

TABLE #1
Summary of Assessment Measures and Corresponding Dimension of the T-Double ABCX Model used in the Redington (1992) Study.

Instrument	Description	Dimension of T-Double ABCX
Parenting Stress Index (PSI)	Uses a Likert scale to assess the degree of stress in the parent child dyad. 50 items are separated into six subscales.	aA Factor (Pile Up)
Family Stressors Index (FSI)	A list of 10 events and family transitions that the family may have experienced in the past twelve months. Developed specifically to address the pile up dimension of the model.	aA Factor (Pile Up)
Family Inventory of Resources for Management (FIRM)	Participants are asked to rate 62 items on a Likert scale according to how well the statement describes their family situation.	bB Factor (Personal Support Needs)
Social Support Inventory (SSI)	Respondents are asked to rate the type, source and overall amount of support they receive from various items listed in the instrument.	bBB Factor Family and Social Support Needs
Family Crises Oriented Personal Evaluation Scales (FCOPES)	Participants rate how well various statements describe their attitude and behaviour in response to various challenging situations. 30 items.	Cc Factor Reframing Subscale
Coping Health Inventory for Parents (CHIP)	45 statements of behaviour are divided into the three different coping patterns. Parents are asked to rate how helpful they have found the behaviours to be in managing challenging situations in the home.	PSC Factor Coping - Explaining to Others
Life Orientation Test (LOT)	Designed to measure optimism about general life events. Parents are asked to state their level of agreement with 12 statements on the test.	cCC Factor Information Needs
Family Assessment Measure (FAM III)	A self report instrument that offers information on the strengths and weaknesses of the family system. 50 items in six subscales	xX Factor Family Adaptation

Bristol (1987) also used the T-Double ABCX model in a study of parents of children with autism, and found that it was an effective way of conceptualizing the process of adaptation in families. A study conducted by Orr et al. (1991) identified a causal relationship among the components of the T-Double ABCX model. They employed a path analysis of the model with 86 families raising children with a mental handicap. These researchers found that it was the family members' perception ("cC" factor) of the pile up of stressors that had the greatest impact on the overall functioning and adaptation of the family system. These studies have shown that the T-Double ABCX model provides a framework that interventionists can use to better enable them to empower family members to meet their needs in constructive ways (Deardorff, 1992).

The Family Focussed Approach

In the past, the provision of services to families of children with special needs has focussed most of the intervention directly on the child (Bazyk, 1989). This child centred approach was often established, directed and evaluated primarily by the various professionals involved with the child. The family members were thrust into the roles of givers and receivers of information (Leyser & Brobst-Cole, 1984), therapists conducting structured programs in the home environment (Benson & Turnbull, 1988; Lyon, 1989); agents of socialization, helping their children become integrated into schools and the community (Winton, 1986), and hosts to a variety of service providers who wished meetings in their offices or the family members' homes (Barnett, 1989). Parents often felt frustrated, inadequate and overwhelmed by the excessive demands placed upon them by well meaning professionals (Winton, 1986). Most of all, parents believed that their values and priorities were being discounted or trivialized, that their thoughts and ideas were not being listened to (Stonestreet, Johnston, & Acton, 1991), and at times felt that they were actually being blamed for their child's disability or delayed progress (Ferrell, 1985).

Current research and intervention programs are now recognizing the valuable role that family members play in the overall well-being of the child with special needs; not as para-professionals, but as parents, brothers, sisters and extended family members (Bailey, Winton, Rouse, & Turnbull, 1990; Dunst et al., 1988; Raver & Kilgo, 1991). This recognition has resulted in a shift from the child centred to a family focussed service delivery system (McGonigel, Kaufmann, & Johnson, 1991). This progression in the delivery of intervention services is not however, without some growing pains. Parents and interventionists often have differing views on what constitutes the best interest of the child (Bailey, 1987; Stonestreet et al., 1991). It takes skill, patience and understanding to access resources in a complex service delivery system, and time to deal with the many activities and resources involved with the child who has special needs (Dunst et al. 1988). Often, the training and life experience of interventionists and parents does not prepare them to work together in such intense circumstances (Beckman & Bristol, 1991). It will take time for both parents and professionals to master the skills needed to join together as true partners in education for children with disabilities (Stonestreet et al., 1991).

Dunst et al. (1988) describe seven characteristics of interactions that may help empower family members to take a leadership role in meeting their own needs. First of all, interventionists must realize that every interaction with parents holds the opportunity to convey a philosophy of equal partnership. Second, all communication must reflect an attitude of trust and respect for the family members. Conversations between parents and interventionists must be honest, address the priorities expressed by the parents and focus on seeking solutions (not causes) to the concerns raised by family members in order to comply with a family focussed approach. Sixth, helpful solutions will be expressed as actions so that family members can identify concrete ways of meeting their own needs. Last, interventionists will portray their respect for families by holding the information on family matters in the strictest confidence (pp. 52-54).

Models of Parental Partnership and Interagency Collaboration

A challenge now exists in the field for interventionists to learn to form partnerships with parents in ways that truly appreciate and incorporate the skills, values and priorities of all family members. The complex tasks involved in forming these partnerships is illustrated by the number of issues raised in the literature regarding this topic. Some of the questions to be answered by researchers, interventionists, policy makers and parents are:

1. Who (parent or interventionist) should have the ultimate decision making power in the partnership (Goodman & Hover, 1992)?
2. What roles are appropriate for each party (McGonigel et al., 1991)?
3. How is the balance of roles and responsibilities among parents and interventionists best achieved (Bailey, 1987; Raver & Kilgo, 1991)?

Goodman and Hover (1992) state that parents and interventionists can have equal power in a relationship without being partners. They propose a model based on the type of relationship an individual has with an accountant, lawyer or doctor. In this type of relationship, the client solicits the expertise of the professional, pays for it and accepts or rejects the advise or proposed treatment plan. The client has total control over the decision to accept and/or implement the procedures outlined by the professional. Their critique goes on to state that the current models of parent professional partnership (in the field of early childhood special education) reverses each of the above conditions and renders the notion of parental power as "fictional".

Other articles however, outline creative strategies used by interventionists to respect the needs, values and decision making abilities of family members. McGonigel et al. (1991) state that the amount of information divulged by family members should be strictly voluntary and that families should lead the process of having their needs met. In that way, interventionists only work with information that the family members want them to have, thus protecting the family's privacy and decision making power. Dunst et al. (1988) state that by acquiring certain skills and knowledge, professionals may be more effective when helping families enhance the educational program of their child with special needs. These researchers assert that help is more likely to be accepted when it is positive, proactive, asked for by family members, and fits into to the family's routine, philosophy and priorities. They also proclaim that family members should be able to reject help and advice if they do not think it is appropriate for their family at that time.

The literature is consistent in declaring that parents should have the final say when making decisions that affect their child and their family. This is not to say that interventionists should abdicate their responsibility for offering suggestions that they believe will be of ultimate benefit for children (Allen & Stefanowski-Hudd, 1987), but that parents have every right to reject these suggestions without fear of losing access to programs or interventionists (Goodman & Hover, 1992).

Throughout the literature, it has been recommended that parents take on the roles of: decision maker, advocate, case manager, program evaluator and record keeper (Allen & Stefanowski-Hudd, 1987; Beatty, 1993; Hamre-Nietupski, Krajewski, Nietupski, Ostercamp, & Openheim, 1988). Perhaps the parental role that has received the most attention has been the role of "teacher". Some articles proclaim that training parents to carry out various therapies and educational strategies in their home environments has been the key to improving the behaviour and development of children with special needs (Leach & Swerissen, 1986; Muir & Milan, 1982). Other reviews of this practice however, have identified that parents often experience feelings of increased stress and decreased enjoyment when interacting with their children after being instructed on ways to enhance their child's development at home (Allen & Stefanowski-Hudd, 1987; Winton, 1986). Although parent training continues to benefit parents and children if its focus is on functional, incidental strategies (Benson & Turnbull, 1988), parents have stated their preferential role as that of *parent,* and not that of intervener (Raver & Kilgo, 1991). Parents have also stated that appropriate roles for interventionists involve providing support, information and knowledge so that parents will be better able to make decisions about services for their child (Able-Boone, Goodwin, Sandall, Gordon, & Martin, 1992).

In an equal, effective partnership parents feel they are in control of the delivery of services (Dunst et al., 1988) and are able to recognize and appreciate their own expertise as parents, educators and advocates for their child (Stonestreet et al., 1991). This can be achieved through the delivery of family focussed services that: (a) respond to the needs of the family instead of having the family adapt to the structure of the system; (b) assist families in identifying and building on their capacities and resources; (c) make adequate resources, supports and information available to family members and (d) help to develop family members' sense of self-esteem, internal control and problem solving abilities (Beatty, 1993, p. 75). The knowledge and skills of the interventionists and the effectiveness of early childhood programs are maximized in relationships with family members where open and honest dialogue exists and mutual trust and respect is fostered (Raver & Kilgo, 1991; Stonestreet et al., 1991).

Since family needs are multi-dimensional (Frey et al., 1989) and no one interventionist has the entire repertoire of skills needed to meet these needs (Bailey et al., 1989), parents will inevitably interact with a large number of agencies once their child has been diagnosed with a disability. The parent/professional partnership that forms to create an IFSP must also be able to collaborate with parents and interventionists from other agencies. Although there are some barriers to interagency collaboration, (such as protectionist attitudes of some staff members, lack of experience and understanding about the processes and benefits of collaboration) effective models of collaboration can enhance the goals of individual families and early intervention programs alike (Lowenthal, 1992). Parents state that information about and access to a wide variety of services is an important goal in the delivery of family focussed intervention (Able-Boone, Sandall, Stevens, & Fredrick, 1992). Agencies may respond to this need by: (a) developing program, policy and service objectives that foster interaction among agencies; (b) clearly define their target population and (c) incorporate wide spread staff training on the benefits of and the principles, attitudes and skills needed to implement effective interagency collaboration (Lowenthal, 1992).

Assessing the Strengths and Needs of Families

In the past, assessment measures were used to determine areas of deficit in children with disabilities (Guess & Noonan, 1982) and areas of pathology in their family members (Freeman, 1989). This focus lead to the belief that all families of children with special needs were in a desperate state of crisis and that those interventionists who worked with these families had no hope of ever having a positive influence on family functioning (Freeman, 1989). Fortunately for family members and interventionists, the current focus on assessment seems to be shifting away from seeking answers to why families fail and towards discovering why so many families cope so well with the excessive demands placed upon them (Bernheimer et al., 1990; McCubbin & Patterson, 1981). Even though the goal of family assessment is currently aimed at better understanding the dynamics of families, creating resources and developing effective support systems the use of assessment measures with family members can be controversial (Swick, 1984).

Some researchers have raised serious concerns regarding the use of assessment measures with parents of children with special needs. These researchers state that the practice of assessing family members can lead to feelings of loss of privacy, raise family members' expectations about the availability of resources to unreasonable levels, convey unintentional messages about dysfunction within the family (Slentz & Bricker, 1992) and may lead to the inappropriate definition of problems within the family (Bernheimer et al., 1990). Goodman and Hover (1992) state that the use of assessment measures is unnecessary and can interfere with the development of effective parent/professional partnerships. These researchers cite examples where the measures have been used for purposes other than which they were intended, without parents understanding how the information from the assessments would be used, and without allowing parents to make an informed choice about whether or not they would like to complete the assessment forms. They have outlined the misuses of assessment measures and their cautions raise interesting issues regarding ethical use of these instruments with family members.

Formal assessment measures do however, have an important role in the development of IFSP's (Beckman & Bristol, 1991). Assessments can: (a) provide information on the family's resources, priorities, concerns and unique characteristics (Olson & Kwiatkowski, 1992); (b) better identify the programs and services that would be most beneficial to the child with special needs and her/his family (Dunst et al., 1988; Olson & Kwiatkowski, 1992); (c) help interventionists evaluate the effectiveness of their interaction (Bailey & Simeonsson, 1988); (d) ensure that the IFSP accurately reflects family goals; and (e) ultimately lead to greater benefits to the child (Garshelis & McConnell, 1993). Current research shows that professionals do not accurately predict the needs and resources expressed by family members (Garshelis &

McConnell, 1993). These researchers recommended that surveys be combined with personal discussions to ensure that services are effectively delivered to family systems.

In another study, parents identified a preference for written surveys over personal interviews and felt comfortable with the length of the assessments used in the study (Sexton et al., 1991). (The surveys used in the Sexton et al. [1991] study were; the Family Needs Survey, the Family Needs Scale and the Family Functioning Style Scale.) Approximately 50% of the interventionists who participated in the Sexton et al. (1991) study believed that the surveys were too long for the parents to complete. However, approximately 90% of the parents in this study stated that they felt the surveys were an appropriate length. It is clear that the best people to identify family needs and resources are the family members themselves. Identifying these needs may be a complicated and overwhelming task, so formal assessment measures can be used as tools to assist in this process.

Although a wide variety of assessment measures have been used and advocated in the literature (Bailey, 1987; Dunst et al., 1988), research documenting the practicality of these measures has been very limited (Bailey & Blasco, 1990). Slentz and Bricker (1992) highlight the need to identify and use only those instruments that will directly lead to the delivery of functional services for the child with special needs. The literature continues to outline the need for specific, practical methods of incorporating assessment data into IFSP goals (Bailey, 1987).

The barriers to effective family assessment may be overcome by implementing sound, family focussed practices in the assessment process (Bailey & Simeonsson, 1988). Several factors may influence how successfully assessment data is transformed into functional IFSP goals. First of all, it is vital that those who complete the assessment measures are fully aware of how the information on these measures will be used (Dunst et al., 1988). This type of informed consent may lead to the development of a mutually trusting collaborative relationship between the parents and the interventionist. Second, information about the assessments may help parents to see the positive aspects of the assessments. The more favourably parents view the assessment tools, the more likely they are to find the information provided within these surveys useful (Bailey & Blasco, 1990).

Third, parents should be able to choose which assessment measures they wish to complete (Bailey & Blasco, 1991). This finding suggests that neither program staff nor funding regulations should *require* parents to provide information on written surveys, but rather respect their wishes to provide only those details necessary to develop an IFSP suitable to their needs. Interventionists need to ensure that parents do not become overwhelmed by the assessment process (Slentz & Bricker, 1992). This may be achieved by providing family members with complete information regarding the purpose, procedure and terminology associated with each assessment measure.

Finally, written assessments of family needs and strengths must be complemented by observation, open ended conversations and the development of a mutually supportive relationship between the parents and the interventionist. Several researchers, (e.g. Bailey et al., 1989; Dunst et al., 1988; McGonigel et al., 1991; Olson & Kwiatkowski, 1992) stressed the importance of building rapport between the parents and the interventionist. Dunst et al. (1988) defined the assessment process as a *craft* that interventionists must practice throughout their career. Parents have expressed a great deal of appreciation for those interventionists who took the time to listen to and support the triumphs and struggles they faced in their day to day lives (Barnett, 1989).

Assessments, Stress and Family Functioning

A major barrier to providing helpful services to families has been to focus too narrowly on only one or two aspects of family functioning. In the past, the construct of *stress* has been a target of many studies (Dyson, 1991; Frey et al., 1989; Friedrich & Boriskin, 1978; Glaser & Bentovin, 1979; Hanson & Hanline, 1990; McClellan, 1991; Redington, 1992). Some researchers concluded that parents of children with special needs experienced abnormally high levels of stress and that this stress was positively correlated with their potential to abuse their children (Friedrich & Boriskin, 1978; Glaser & Bentovin, 1979). Not only did this inaccurate view tend to blame the victim of abuse for "causing" the stress, it also interfered with the development of more effective abuse prevention programs (Sobsey, 1990).

Studies conducted on the abuse of people with disabilities showed that the majority of these offenses occurred in institutional (not home) settings. These studies also showed that psychological deviancy among abusers was tied more closely to incidents of abuse than were high stress levels (Sobsey, 1990). Dyson (1991) concluded that high levels of stress did not necessarily predict dysfunction within a family system and that many families developed very competent coping strategies in response to the stressors they faced.

Recent studies have systematically assessed the sources of stress, and highlighted practical ways of reducing it within these family systems. Hanson & Hanline (1990) stated that the presence of a child with special needs had less impact on the stress experienced by parents than did socio-economic status, spousal relationships and personal problems. Accessing community resources such as respite care (Cavanagh & Ashman, 1985), fostering the development of feelings of power and control over their situation (Affleck, McGrade, Allen, & McQueeney, 1985; Frey et al., 1989) and implementing family members' ideas for meeting their own needs (Zeitlin et al., 1987) are strategies that have had a positive correlation with enhancing the coping strategies of parents.

Individualized Family Service Plans

A family focussed approach to intervention involves identifying and utilizing the needs and resources of the entire family system and documenting them in an IFSP (Dunst et al., 1988). Underlying the development of an IFSP are the assumptions that: (a) the child is viewed in the context of her/his unique family system; (b) parents are involved in decision making; and (c) there is a clear recognition that the needs of the child can be at least partially met by formal and informal support systems (Bailey et al., 1990, p. 16). In order to empower family members to direct the delivery of services into the family system, it is imperative that interventionists believe that parents have the ability to identify their own needs (Zeitlin et al., 1987). Respecting the choices of parents and acting as facilitators instead of problem solvers are some of the ways interventionists may be able to help family members achieve the goals listed on the IFSP (Dunst et al., 1988).

There are many appropriate formats for an IFSP. It is important that each program team develop an outline that best merges the needs of the individual family system and the delivery of appropriate services. The common elements of all IFSPs are that: (a) family members and interventionists work collaboratively to develop the goals (Bailey, 1987); (b) the goals are written in behaviourial terms so that accountability and evaluation of the process can be determined (Bailey et al., 1990); and (c) the principles of a family focussed approach are integrated throughout the document (Dunst et al., 1988).

Parents feel empowered to take a leadership role in their child's educational program and positively acknowledge their contributions to their child's progress if they actively participate in the development of a high quality IFSP (McGonigel et al., 1991; Raver & Kilgo, 1991). A high quality IFSP is designed so that it responds to the priorities of the family members, instead of requiring them to adapt their lifestyles to accommodate the structure of the service being offered to them (Raver & Kilgo, 1991).

Also, IFSPs better enable family members to access services available to them in the community. One study (Mahoney et al., 1990) documented that families who had developed an IFSP showed a marked increase in the amount of public assistance they requested and received. It has been shown that active coping strategies (eg. establishing informal support systems) contributed more to successful family functioning than did more passive activities such as merely accepting offers of support (Bristol, 1987). Interventionists may increase their ability to empower family members if they encourage parents to take active roles in the development and achievement of goals in an IFSP.

Summary

The process of developing a useful and inclusive IFSP can present many challenges to interventionists. They must: (a) be able to identify and balance appropriate roles and responsibilities for parents and professionals, (b) be fully informed about a variety of issues, (c) be able to collaborate with staff from other agencies, (d) be able to use a variety of strategies that identify family needs and resources, (e) organize the information in a reliable, meaningful way; and (f) convey this information back to parents in a clear, practical manner which enables parents to direct the efforts of the interventionists. The research conducted for this thesis incorporated family systems theory, the T-Double ABCX model of family adaptation and the sound practices associated with a family focussed model of service delivery to develop a process of creating an IFSP. It is hoped that this process will empower parents to meet the needs of their family members in positive and productive ways.

CHAPTER III - METHODS AND PROCEDURES

As the movement towards family empowerment and a family directed service delivery system escalates, it is important to discover ways for family members to easily and confidently use the insights discovered through assessments to better meet the needs of their entire family system. This study incorporated a summative evaluation process (pre-test/post-test paradigm) combined with survey research to evaluate the effectiveness of this IFSP procedure. This chapter will describe the characteristics of the assessment measures used, the components of the T-Double ABCX model to which they correspond and the questions that guided the research in this study. The descriptions of the instruments are largely taken from summaries compiled by Redington (1992, pp.34-41). The validity and reliability scores for each of the measures can be found on Table 2. A description of the families who participated in this study and an overview of the steps involved in developing IFSPs with the families are also provided in this chapter.

TABLE #2

Table of Reliability and Validity Measures of the Instruments used in this Study

Instrument	Reliability (Overall Scale)	Validity
CHIP	.71 to .79*	(Not found)
FAM III	.95**	.60 to .87**
F-COPES	.86**	.64 to .87**
FIRM	.89*	.46 - .25* (Correlation coefficient of FIRM subscales with Family Environment Scales.)
FSI	.81** .30 - .73 (Range of subscale reliabilities)	.60** (Correlation coefficient with Family Inventory of Life Events and Changes)
LOT	.76**	(Not found)
PSI	.95***	.44***
SSI	.81** (Test-retest reliability)	(Not found)

Sources:		
	*	McCubbin & Patterson (1983)
	**	Redington (1992)
	***	Loyd & Abidin (1985)

Describing and Measuring the Pile-Up of Stressors - The aA factor

Family systems are constantly adjusting their needs and demands according to the events they face over a period of time. Often, the system deals with a number of stressors at any one time, and this *pile-up* of events is referred to as the aA factor (McCubbin & Patterson, 1981). These authors outline three types of stressors that may contribute to *pile-up*. The initial stressor is identified as the life event that moves the system into a state of crisis (*"a" factor*). The presence of the initial stressor demands that the system makes some type of adaptation or adjustment. Second, normative life changes such as children going through developmental stages, spousal relationships or job stresses may occur concomitantly with the initial stressor, but may be independent from it. The third type of stressor set is associated with the changes the family system makes as it tries to adapt to the initial stressor situation. These last two stressor categories join to form the (*"A" factor*) (McCubbin & Patterson, 1981). Changes in communication patterns among family members, increased time spent with professionals and a decrease in the amount of time spent at home may all be events that could be included in the this last group of stressors.

Two separate measures were used to measure the pile-up dimension of the model. The *Parenting Stress Index (PSI)* was developed to provide a "measure of relative magnitude of stress in the parent-child system" (Loyd & Abidin, 1985 p.169). The *Child Characteristics Domain* category lists 50 items that identify possible qualities of the child that may add stress to the family system. Respondents are asked to answer each question by circling a number from **1-5**, with **5** being that the parent "strongly agrees" with the question and **1** being that the parent "strongly disagrees" with the question. These 50 questions are broken down into six sub-scales: (a) Adaptability - examines the way the child adjusts to changes in her/his environment; (b) Acceptability - examines the match between the child's appearance, behaviour and development and the parents' expectations of these characteristics; (c) Child Demandingness - examines how much of the parents' time and energy is spent on meeting the needs of the child; (d) Child Mood - examines the parents' perceptions of the child's predominant emotional state; (e) Child Distractibility/Hyperactivity - examines parents' perceptions of the child's ability to attend to a task, follow directions, and overall level of activity; (f) Parent Reinforcement - examines the amount of feedback parents get when interacting with the child.

Typically, parents of children with disabilities score above the 90th percentile in the *Child Characteristics Domain* indicating that they may be experiencing an above average level of stress within their family system (Loyd & Abidin, 1985). According to the standards of the assessment, a score above the 90th percentile does not necessarily indicate family dysfunction. It may however, indicate the potential for a crisis situation to develop if there is a high score in both the *Child Characteristics* and the *Parent Characteristics* domain (Loyd & Abidin, 1985).

The *Family Stressors Index (FSI)* is a list of 10 normative life events and changes. Respondents were asked to indicate which of the events they had experienced in the last 12 months. The *FSI* was specifically developed to measure the *Pile-Up* factor of the T-Double ABCX model, is short and relatively non-intrusive (McCubbin, 1991).

Describing and Measuring Family Resources - The bB Factor

The family resources are those characteristics (strengths) that help the system meet the demands placed upon it through everyday activities and through the presence of the crisis event. These resources may connected to an individual within the family, (e.g. organizational, cognitive or communication abilities), the family system itself, (e.g.closeness, flexibility) or the community in which the family system functions (e.g. medical facilities, relief services and social support networks) (McCubbin & Patterson, 1981). The family system may possess these resources prior to the onset of the crisis event (*"b" - existing resources)*, or these may be developed in response to the *pile-up* of stressors *("B" - new resources).*

The *Family Inventory of Resources for Management (FIRM)* was one of two measures used to partially identify the strengths of the family as perceived by the parents (McCubbin & Patterson, 1981). It contains 98 items that focus on the areas of: (a) Esteem and Communication, (reveals ways in which family members communicate with, support and encourage each other); (b) Mastery and Health, (measures the family members' abilities to cooperate, provide mutual support and maintain emotional and physical health within the family); (c) Extended Family Social Support, (identifies whether or not family members find their relatives to be supportive and helpful); and (d) Financial Well Being (measures the perception of family members regarding their ability to meet financial obligations) . Only 62 of these items were included in this study since the "Sources of Financial Support" subscale was not used. Parents were asked to rate each of the statements on a 4 point scale with 1 being that the statement did not describe the family well and 4 being that the statement did describe the family accurately.

The *Social Support Index (SSI)* catalogues for parents those resources in their family and community that they find helpful (Grochowski & McCubbin, 1991). It lists twelve possible sources of support (spouse, children, relatives, professionals, church, co-workers, spiritual faith, community groups, special groups, books/media, and other), in five different categories (esteem, emotional, network, appraisal and altruistic). Respondents are asked whether or not they find support from the various sources when feeling loved and respected (esteem) or when developing a sense of security from being in a relationship (networking). A score above "10" for any one category indicated that it was a useful source of support for that parent.

Describing and Measuring the Family Perceptions - The cC Factor

The perception of life events held by family members may be the most significant contributor to the adaptation or maladaptation of the system to a stressor event (Orr et al., 1991). McCubbin and Patterson (1981) break perception of the stressor event into two categories. The first classification of perception (*"c" factor*) is the evaluation of the family members' view of the event that initiated the crisis within the family. The second component of perception (*"C" factor*) is the view the family members hold of the entire crisis situation, including the pile-up of stressors and new and existing resources. The ability of family members to redefine a situation in positive terms (e.g. as a challenge or an opportunity for growth), or assign meaning to the event (e.g."It's God's will") make significant contributions to the system's ability to cope with and adapt to the crisis situation.

Again, two measures were used to assess each family's perception of life events and crisis. The *Life Orientation Test (LOT)* is an instrument that is designed to measure the relative optimism of family members by evaluating their expectations of present and future events (Scheier & Carver, 1985). The test consists of 12 items. Four items are phrased in positive terms, four are phrased in negative terms and there are four "filler" questions that are intended to disguise the underlying purpose of the test. Respondents are asked to rate their agreement with each of the statements on a scale of 1 to 5.

Situational appraisals of events experienced by family members are measured in this study by two subscales in the *Family Crisis Oriented Personal Evaluation Scales (F-Copes).* This instrument helps family members identify the strategies they use in difficult situations (McCubbin, Olson, & Larsen, 1991). The *Reframing* subscale (8 statements) evaluates the ability of family members to define difficult situations in a positive manner to make them more manageable. The active or passive aspects of strategies family members employ to deal with problem situations are addressed through the *Passive Appraisal* subscale (4 statements). Respondents are asked to state their level of agreement with each of the twelve statements on a five point scale.

Describing and Measuring Family Problem Solving - The PSC Factor

The ways in which family members cope with life events is typically not adequately addressed in other models of family functioning (McCubbin & Patterson, 1981). Identifying and analyzing the family system's coping mechanisms can be helpful in assisting family members to deal with present and future crisis situations in positive ways. *Coping* refers to the "behavioral responses of family members and the collective family unit to eliminate stressors, manage the hardships of the situation, resolve the intra-family conflicts and tensions, and acquire and develop social skills" (McCubbin & Patterson, 1981, p.14).

The problem solving and coping strategies used by participants in this study is measured using the *Coping and Health Inventory for Parents (CHIP).* This inventory identifies the activities that family members find helpful as they go about accomplishing the tasks involved when raising a family with a child who has special needs (McCubbin & Patterson, 1981). It lists 45 behaviours and respondents are asked to rate the helpfulness of each statement on a scale of 1 to 4. The scale is broken down in to three sections. The first is that of *Integration, Cooperation and Communication* which addresses the behaviours that strengthen family life and relationships, and lead to a positive outlook of life with a child with disabilities. The *Support, Esteem and Stability* subscale identifies behaviours that help parents develop relationships with each other, engage in activities that build feelings of self worth and manage pressures and tensions. The third category is that of *Medical Consultation and Communication.* This last category helps parents recognize whether or not they have developed relationships with health care professionals and/or other parents of children with special needs.

Describing and Measuring Family Adaptation - The xX Factor

McCubbin and Patterson (1981) describe family adaptation as balance among the demands and capabilities of the family system as they are achieved through reciprocal relationships among members of the family as they connect with each other and the systems in the environment. The concept of adaptation lies on a continuum with *bonadaptation* being when the system has achieved the balance among needs and resources, and *maladaptation* when balance within the system is not achieved, or results in a loss of family autonomy or family integrity (p. 10).

The concept of overall family adaptation was assessed in this study by using the *Family Assessment Measure (FAM)* . This measure consists of 50 statements in seven categories that address various aspects of family functioning (*Task Accomplishment, Role Performance, Communication, Affective Expression, Affective Involvement, Control* and *Values and Norms*). This instrument also includes a *Social Desirability* and *Denial* scale to warn researchers about potential inconsistencies in the responses of participants. Scores that fall within +/- 1 standard deviation from the mean are considered average. Scores that fall above one S.D. would be considered to be in the "clinical" range of functioning. Scores that fall below one S.D. would be considered to be strengths of the respondent. Researchers would also want to watch for discrepancies among scores of mothers and fathers. This may be indicative of marital discord (Skinner, Steinhauer, & Santa-Barbara, 1983). Results from this measure should be treated with caution if the scores on the *Denial* and *Social Desirability* subscales do not fall within the average range.

Research Questions

The following questions guided the research in this study.

1. Did parents find it helpful to receive information from the various family assessment instruments they have completed?

   This question was assessed through participants' responses contained in the Final Questionnaire (See Appendix A).

2. Did participation in this project result in any reduction in stress level as indicated by the post-test assessments administered at the conclusion of the study?

This question was assessed through participants' responses contained in the questionnaire and through completion of the FAM, PSI and FSI.

3. Were research participants able to achieve the goals they had listed on the IFSP form? Why or why not?

   This question was assessed through participants' responses contained in the questionnaire and completion of the FAM.

4. Did parents feel more confident when interacting with service providers after participating in this study?

   This question was assessed through participants' responses contained in the questionnaire and completion of the CHIP.

5. Did parents feel more confident and positive about their abilities to interact with and advocate for their child with special needs after participating in this study?

   This question was assessed through participants' responses contained in the questionnaire and completion of the LOT and F-COPES.

6. Did the research participants see a clear connection between the family assessment data and the information they wrote down on the IFSP form?

   This question was assessed through participants' responses contained in the questionnaire.

7. Were there any changes in the needs identified in the assessment measures and those written down by participants on the IFSP form?

   This question was assessed through participants' responses contained in the questionnaire and completion of the LOT, PSI and FIRM.

8. What suggestions do parents have regarding improving the development and implementation of an IFSP.

   This question was assessed through participants' responses contained in the questionnaire.

Description of Participants

Potential research participants were identified from the parents studied by Redington (1992). Parents who scored in the clinically significant range on the *Family Stress Index (FSI)* and the *Family Assessment Measure (FAM)* were among the first invited to participate in this study. Eight families met this criterion. Five of these families (four two-parent and one single parent) gave their consent to participate in the study. Four mothers completed the final questionnaire and assessment measures. (One family withdrew their consent to participate in the study after the second home visit. only information from mothers who completed the study was used in the analysis of this research.)

Participants were all parents of preschool children (aged 4-6 years) who have some type of disability. All families were being served by a large rural agency associated with the provision of family and early childhood preventative health and support services (herein referred to as the *agency*) and/or a community early childhood education program (ECEP). Each contact with research participants followed a pre-set list of procedures based on sound family focussed guidelines outlined in the literature (See Appendix B - Protocol for Home Visits).

The research participants live in two rural communities in Alberta. Two of the families reside on farms and two live within the limits of a town. Two of the mothers work outside of the home, two mothers operate small businesses out of their home and one mother is a full time home maker. (One of the mothers works both outside of the home and operates a small business.) There were three two parent families and one single parent (mother) family who participated in this study.

The research participants established the time of the home visits and determined who would participate in the discussion and completion of the assessment forms. Only one visit (out of the total 16) included both parents. The father in one family participated in the initial visit and contributed to the discussion regarding the accuracy of the pre-test assessment results. Only the mothers chose to complete the Final Questionnaire and assessment measures, although two of the three fathers signed forms consenting to participate in the study.

All of the fathers are employed outside of the home. Two fathers also do some farming, in addition to their other employment. The age of the mothers ranges from 25-35 and the age of the fathers ranges from 34-35. The education level of the mothers ranges from grade 10 to a post-secondary diploma and for the fathers, the level of education ranges from grade 10 to a seven year professional training degree.

The children with special needs in this study (3 girls and 1 boy) range in age from 5-6 years old. All of the children were enrolled in an early education program and receive some additional therapy/programming that pertains to their specific delays in development. Two of the children in this study are hearing impaired (one with a mild impairment and one with a profound impairment), and two children have cerebral palsy. One of these children is only mildly affected with cerebral palsy, while the second child is profoundly affected by this syndrome and has sensory deficits in addition to her cognitive and motor disabilities. In two families, the child with special needs is the oldest. In one family the child with special needs is the youngest, and in the fourth family the child with special needs is the middle child. All children are living with their biological parents.

Procedures

This IFSP process was piloted by implementing the following procedures:

STEP #1 - Preparation

Staff from the *agency* were contacted and the purpose of and methods involved in this study were outlined (See Appendix C). Their support and assistance were sought and lines of communication between the researcher, participants and *agency*/ECEP staff were discussed. The role and responsibilities of the researcher were clearly explained and throughout the meeting, *agency* staff were invited to provide feedback on ways to improve the process to better meet the needs of the clients they serve.

STEP #2 - Contacting Participants

A list of potential research participants was given to staff at the *agency*. The staff had volunteered to contact the perspective participants and make a preliminary inquiry as to whether or not these parents would be willing to take part in the study. Staff from the *agency* distributed the consent forms to interested families, then contacted the researcher with a list of families who had been given consent forms The researcher then contacted each of the families to arrange a time for the initial visit.

Once the list of interested participants had been received from the *agency*, the researcher contacted potential participants by phone. The general time line, purpose and activities of the project were outlined. If parents agreed to take part in the study, a letter outlining the steps in the process and consent forms were mailed out to them. (See Letter of Introduction and Consent Form in Appendix D.)

STEP #3 - Developing the Family Profile

Data from the Redington (1992) study was reviewed by the researcher and her advisors and the scores of consenting participants was summarized on the Family Profile and Summary (Nelson, 1992) (See Appendix E). These scores were used as pretest data in this study. The Family Profile and Summary was completed by the researcher prior to the initial home visit.

STEP #4 - Initial Visit

Each consenting research participant was contacted by phone to arrange a mutually convenient time for an initial home visit. At this visit, information from the previous assessment measures (completed by the parents in the Redington [1992] study) was presented via the Family Profile and Summary.

A Glossary of Terms (See Appendix F) that defined the vocabulary used in the assessment measures was also provided to and reviewed with each parent. This glossary was developed to further employ the principles of empowering parents by providing them with information about family functioning that was as complete and comprehensible as possible. Cranwell and Miller (1987) discovered that parents generally did not ask for clarification of terms they did not understand. The Glossary of Terms was reviewed as a matter of course throughout the first visit. Parents were not asked whether or not they felt they needed the terms explained.

Parents were invited to discuss their ideas and perceptions regarding the information listed on the Family Profile and Summary. If parents did not find the Family Profile and/or Summary to be accurate representations of their current situation, they were invited to re-write any appropriate family assessment measure(s) or verbally state the changes they wished to make on the Family Profile and/or Summary. Participants were then presented with the IFSP Form (See Appendix G) and asked to transfer what they considered to be relevant information from the Family Profile and Summary to the appropriate spot on the IFSP Form. A discussion of goals and ways to achieve those goals also took place at the first home visit. At all times, the perceptions and priorities of the parents were given the utmost consideration (Protocol for Home Visits, Appendix B). When parents identified goals that required some follow-up or community support, they were encouraged to contact their community interventionist to assist them in achieving these goals.

STEP #5 - Follow up Contacts

Two follow up contacts were provided to each family (April through June). The purpose of these contacts was to clarify and elaborate upon the strategies and activities that parents listed on the IFSP Form and support their efforts in accomplishing these goals. Again, the principles associated with family focussed intervention were employed throughout these visits.

STEP #6 Final Home visit and Assessment of the Process

Parents were asked to complete a questionnaire (See Appendix A) and a set of assessment measures that corresponded to the T-Double ABCX framework.

Parents were asked if they had any questions regarding any aspect of this IFSP process and were asked if they wanted any follow-up contact after the study concluded. The participants were thanked for their involvement in the study and were encouraged to continue to build on the strengths they demonstrated throughout the project.

Data Collection

Pre-test data were obtained from assessment forms used in the Redington (1992) study. The post-test data were collected by the researcher during the final home visit. To facilitate completion of the forms, parents were asked if they wished to have the questions read aloud to them. Parents were provided with the set of final assessment measures at the third home visit, so that they could complete them according to their own time schedule. Some parents did complete these forms during the final home visit. All parents were asked to complete the Final Questionnaire during the last home visit. Participants recorded their responses in a way that obscured the view of the researcher. If parents wished to fill out the forms in their own time, a self addressed envelope was provided for them and parents were asked to return the forms within two weeks. Follow up contacts were made until the forms were returned or parents chose to withdraw from participation in the study.

The evaluation of this model of developing an IFSP was accomplished by readministering the measures used in the Redington (1992) study and asking research participants to respond to a questionnaire developed specifically for this project. A summary of the pre and post-test assessment results can be found on Table 3. Results obtained through the Final Questionnaire are contained in Appendix H. Through participating in this process, it was hoped that family members would feel better equipped to take a leadership role in establishing and directing their child's educational program, as well as taking steps to have their own needs met in ways that fit with their current priorities and lifestyles.

Data Analysis

The research questions were answered by combining data from the Final Questionnaire and assessment measures. Due to the low number of participants in this pilot, detailed statistical analyses have not been conducted. Another important aspect of the evaluation of this project is the summary of the discussions and comments that occurred during the visits. The goals listed

Table 3. Comparing Normative Samples, Pre Test and Post Test Overall scores of Assessment Instruments

	Normative	Pre Test (Mothers)		Pre Test (Fathers)		Post Test (Mothers)	
Subscale	Range	Range	Mean	Range	Mean	Range	Mean
FAM	40-59	44-63	51.75	50-59	53.3	48-56	51.5
FSI	3-18	4.1-25	16.4	4-36	18	4-31.7	20.2
PSI	78-116	92-127	113.75	92-143	113.3	102-138	116.75
LOT	15-25	8-28	21	18-21	19.67	7-27	20.5
F-COPES							
Reframing	25-35	25-37	31.25	21-36	29	25-35	32.25
Passive Appraisal	6-10	11-19	15.75	13-20	20.3	14-20	17.75
CHIP							
Integration	25-55	32-55	44	26-54	44	28-53	41.25
Support/Esteem	16-40	28-43	36.25	25-40	31.67	22-40	32
Medical Consult.	8-22	16-22	19.5	9-20	15.67	14-20	17.5
FIRM	90-150	59-123	102.75	113-118	116	69-127	112.5

by parents, the identification of their own strengths and needs, and the processes they employed to achieve these provide useful qualitative information on the practicality of the process piloted in this study. A summary of these visits and inferences as to their significance will be detailed in the Results and Discussion chapters of this thesis.

Confidentiality

Confidentiality of all information obtained in this study was ensured through the following procedures. The names of the participants were not used outside of the participants' home and did not appear on any document that resulted from this research. Research participants were coded so their names did not appear on any assessment measure or paper that left the family's home. The master list matching codes and the names of the research participants was kept in a locked location by one of the thesis co-advisors. Participants were reminded of their option to withdraw their consent to participate in this study at every home visit/phone contact.

No information on research participants, their scores or goals listed on the IFSP was discussed with people other than those involved directly with the project at the University of Alberta. Parents were encouraged to share any of the information discussed at these visits directly with their interventionists. Any questions that arose throughout the course of this research were only be discussed with Dr. Kysela, or Dr. McDonald, co-advisors to this thesis project.

Conclusion

The complexity of the processes used in this study required the implementation of specific and systematic procedures. Detailed lists of protocol were in place, but each visit varied in its content and format according to the individual needs and priorities of the families involved in the study. Throughout this project, the focus of the visits as set by the parents took precedence over the predetermined expectations of the researcher. The implications of this priority and the overall results are discussed in the following chapter.

CHAPTER IV - RESULTS

The results of the current study are presented in this chapter. The details of the home visits provided to research participants are summarized. The information gained from these visits was extremely helpful when answering the research questions and making some of the recommendations discussed in the next chapter. The participants' comments, feedback and data from the formal assessments were used to answer the research questions that guided this investigation.

Summary of Visits

All visits followed the Protocol listed in Appendix B. The researcher acted in a role of listener and supporter of family goals and needs. The researcher did not take on any responsibilities typically held by an interventionist (e.g. planning programs for children, connecting the family with community resources, suggesting teaching strategies.). It was felt (by the researcher and her advisors) that interventionist activities would be best completed by the professionals who were already working with the individual families. Some questions were asked of the parents to clarify information or to discover if they knew about resources available to them, but no specific programming suggestions were offered to parents by the researcher. No contact between the researcher and *agency* staff was made after the selection of participants was completed. This procedure was in place to ensure the confidentiality of the information parents shared during the visits and to keep the roles of the researcher and the interventionists clear. At all times, parents were encouraged to contact their interventionist(s) if they felt more information or support was needed by the family.

The length of the visits ranged from 30 minutes to 2 hours. Some of the scheduled visits were postponed due to scheduling changes experienced by the parents. All but one of these visits was re-booked. Three families received four home visits and one family received three home visits. (This family was offered four, but due to their time restraints only three visits were completed.)

On the first home visit, the researcher reviewed the assessment data with the parent(s), as contained on the Family Profile and Summary. In addition, each family received the summary data sheets for the assessments they completed in the Redington (1992) study, and a Glossary of Terms (See Appendix F).

Parents were asked whether or not they had any questions regarding the information and were asked if they thought the information accurately reflected their family's resources and needs. Parents were offered an opportunity to re-do any measures they felt were no longer representative of their family's current situation.

Only one parent requested to re-complete an assessment (the *FSI*). This parent thought that the stress level experienced by her family had decreased since she first completed the measure. Upon scoring the second *FSI*, it was discovered that the overall score decreased slightly, but remained in the above average range.

Parents were then asked to list the strengths and needs of their family and record these on the IFSP Form. All parents asked if they could think about their family's strengths, needs and goals and record them on the sheet before the next visit. Some parents, did however, discuss with the researcher some goals that they either had planned or were in the process of planning for their family system. Some of these goals included: helping siblings understand ways that the child with special needs is included in family activities; helping siblings to feel important and included in family activities and decisions; successfully communicating needs to new service providers who were taking over services previously provided by an agency familiar to the parents; establishing solid transition planning for children entering kindergarten in September; and meeting a variety of scheduled appointments.

On the second visit, all parents apologized for not completing the IFSP Form and asked if that was a problem. The researcher assured them that this was not a problem and that it was important that they felt good about participating in the study without feeling pressure to complete the form if they did not find it helpful. All of the parents who participated in this study said that they made goals and kept "To-Do" lists, but they rarely wrote down names of people who would help them achieve goals, nor time lines for completing the goals. These parents were able to articulate their child and family goals to the researcher and did outline the strategies they were implementing to achieve these goals.

Parents were asked if they wished to complete the IFSP Form at the second visit. Two parents completed the form at this time with the assistance of the researcher. All parents discussed what had happened in their family since the last visit. One mother stated that the goals now revolved around new bedroom arrangements for her older children, one mother stated her goal was to learn to better deal with a relative who she perceived to be undermining her parenting skills, and a third parent stated that her goals were to just keep up with the many appointments, treatments and meetings involved with her child's special needs. The fourth parent indicated a need to improve the amount and quality of communication between she and her husband. Parents were all asked what they would like to do to achieve their goals, what family strengths they could employ to meet these goals, and who they could call upon to assist them in achieving these goals. All parents came up with at least one strategy on their own that they could use to help them reach their goal. Many of these strategies involved calling upon family members, friends or service providers to assist in child care, participate in social activities, or offer advise or access community services.

Two mothers did not write down their goals on the IFSP Form. Both of the mothers stated that they did set goals, and they knew that they were working towards them, but they were just not in the habit of writing down their goals or "to do" lists. It was felt that these parents did follow the procedures proposed in this research, so their data were incorporated into the results of this study.

All of the parents spoke highly of the interventionists who had regular contact with the families. Three parents indicated that they had a great deal of input at their child's school, and although some disagreements arose from time to time, these parents felt that they had sufficient influence with school staff to resolve any conflicts. No parent expressed concerns regarding the service or programming their family was receiving from any agency.

At the third visit, two parents shared the status of their progress towards their goals, and stated that upcoming events took precedence over the previously stated goals. New issues involved changes in staff who worked with the child with disabilities and the recruitment of an aide to provide summer programming. Although the parents did not write these down as goals on the IFSP Form, they very actively and competently dealt with these issues in time for staff to be in place at least one month before they were needed. At the end of the third visit, parents were provided with a set of assessment measures and were invited to complete them before the next visit.

At the last home visit, two parents answered the questions contained in the assessment measures, one parent had completed the assessment package prior to the visit and one parent mailed the completed assessment package to the researcher. All parents were thanked for their participation and were asked if they had any questions or would like any follow-up contact. The researcher asked the participants if they would like a fifth visit to review the post-test assessment data. All parents declined this visit, but requested that copies of the assessment data be mailed to them. A summary of the completed assessments, a Summary, Glossary of Terms and a Thank-you letter were mailed to the families once all the assessment packages had been received by the researcher.

Overall, the parents were very responsive to the visits. They talked openly and honestly about the many issues they were facing in the day to day lives of their family. The visits employed an open ended format that allowed parents to choose the topics they wished to discuss. Throughout the course of the study, parents indicated a number of changes in the goals they established for their family and revealed many strengths and resources they used to achieve these goals.

Answers to Research Questions:

Data from the completed assessment measures have been summarized in Table #3 (See p. 60). This data and information from the Final Questionnaire are combined to answer the following research questions. (A summary of the responses to the Final Questionnaire can be found in Appendix H.)

Research Question #1:

> Did parents find it helpful to receive information from the various assessment instruments they have completed?

Results from the Final Questionnaire indicated that most parents (three out of four) stated that they did find the assessment information helpful. One parent stated that she did not find it helpful because "There's too much [sic] other things going on right now". (This parent was dealing with a number of family issues unrelated to the child with special needs.) Two parents said they **Agreed** that the information was helpful, and one parent said she **Strongly Agreed** with the statement. Comments which the parents provided in response to this question were: (a) "It was a boost to find out that we are doing 'OK' according to someone else. Also, to see the areas of weakness was helpful."; and (b) "Very interesting to see how closely my husband and I matched up. It made me see we aren't really that opposed."

Research Question #2:

> Did participation in this project result in any reduction in stress level as indicated by the post-test assessments administered at the conclusion of the study?

The two questions on the Final Questionnaire that dealt with the parents' perceptions of the level of stress they were experiencing revealed slightly conflicting answers. Three parents stated that they were **Not Sure** that they had less stress after participating in the project. One parent said she **Disagreed** with the statement "I feel less stress now that I have participated in this project" (question #3 in the Final Questionnaire). However, in question #6 ("I feel more stress now that I have participated in this project".), all four parents said that they **Disagreed**. One parent commented that "I may not write our difficulties down, but I am more aware of the thinking process." In light of the slightly conflicting responses, it may be tentatively said that the participants did not appear to experience more stress after participating in this study.

Scores on the *FSI* for three families indicated they had experienced an increase in the amount of potentially stressful life events since they completed the pre-test measures. Two of these families had pre- and post-test measures above the average range established for this instrument. The third family had pre- and post-test scores both within the range that has been determined to be normal for the general population. One family experienced a decrease in the number of stressful life events from the pre- to post-test measures. Both of this family's scores fell within the normal range. The *FSI* only lists potentially stressful life events. It does not identify whether or not the parents consider these events to be stressful, nor does it incorporate any strategies family members may employ to cope with the stressors.

Scores on the *PSI* indicated that the stress related to the tasks associated with parenting increased for two families and decreased for the two other families. Both the pre-test and post-test scores on the *PSI* (total scores) were above average for three of the parents who participated in the study. The fourth parent had both pre and post-test *PSI* scores that fell within the normal range established for this measure.

Overall, post-test scores on the *FAM* increased when these were compared to the pre-test results. It is important to mention however, that the pre-test and post-test scores for these families all fell within the normal range of functioning according to the standards set for this measure (i.e. All overall pre-test and post-test *FAM* scores for these three families were between 40 - 60.) Since all scores fell within the average range, it is uncertain that an increase in the overall score for families on this measure indicated any significant decrease in the level of bonadaptation being experienced by the parents. The fourth parent indicated an increase in the level of adaptation experienced by her family system. Her pre-test score on the *FAM* fell within the clinical range, while her post-test score fell within the normal range. This is a significant increase in the level of bonadaptation being experienced within this family system.

In summary, parents stated that they perceived a decrease in the amount of stress they experienced after participating in the study. The formal measures of stress (*PSI* and *FSI*), however, revealed that there was an apparent increase in stress being experienced by these mothers during the same period of time. Scores on the *FAM* seemed to indicate that all of the respondents were adapting well to the stresses they experienced. Although these results seem to conflict with each other, they are consistent with some of the research. These studies (e.g. Dyson, 1991; Loyd & Abidin, 1985) indicate that although parents of children with special needs experience higher level of stress than those in the general population, they often adapt to these pressures in positive ways.

Research Question #3:

> Were research participants able to achieve the goals they listed on the IFSP form?

Responses to question #8 on the Final Questionnaire indicated that two participants stated the were able to reach their goals, one parent said she did not achieve her goals and one mother said she wasn't sure that she achieved the goals. One parent said she "became more aware of (her) goals" and another parent said that she was able to achieve "Short Term goals...."

In the *Task Accomplishment* subscale of the *FAM* the post-test scores of three mothers decreased when compared to their pre-test scores. This result indicates an improved perception of their ability to meet the needs of family members. Pre and post-test scores for the fourth mother remained the same.

All post-test scores fell within the normal range. Pre-test scores for two of the participants were within the clinical range, and two fell within the normal range established for this measure.

All parents indicated that they perceived themselves to have an ability to meet the needs of their family members according the subscale scores on the *FAM*. However, an examination of the responses on the Final Questionnaire, reveals that only 50% of the participants felt they were able to achieve the goals listed on the IFSP. Given the information in the Final Questionnaire, it cannot be said that all parents felt they were able to achieve the IFSP goals throughout the course of this study.

Research Question #4:

> Did parents feel more confident when interacting with service providers after participating in this study?

In response to question #4 on the Final Questionnaire, two participants said they were **Not Sure** and two participants said they **Agreed** with the statement "I feel more confident when talking with people who work with my child since participating in the project." One parent commented that the "School is helping out a lot with (her) son" and another parent who said she was **Not Sure**, stated that she is "now more aware of (her) family's strengths as (she) advocates for their child in relationship to their whole family."

The *Medical Consultation and Communication* subscale on the *CHIP* revealed whether or not parents found contact with health professionals and parents of other children with special needs to be helpful (McCubbin, 1981). On this subscale, all parents' scores (both pre- and post-test) fell within the normal range established for this instrument. One parent's pre- and post-test scores remained the same, one parent's post-test score increased over her pre-test score and two parents' post-test scores were lower than their pre-test scores.

The results on the *CHIP* subscale indicate that all of the research participants had at least an average level of positive contact with professionals before participating in the study. Since these scores remained in the average range, and half of the mothers indicated that they were not sure they felt more comfortable interacting with professionals after participating in the study, it is unlikely that their participation in this study had any effect on the parents' level of confidence in interacting with professionals.

Research Question #5:

> Did parents feel more confident and positive about their abilities to interact with and advocate for their child with special needs after participating in this study?

The *LOT* was used as a way of addressing this question since it is a relative measure of the meaning a family member attaches to an event. High scores (above 14) indicated a relatively positive outlook towards life events. Scores 13 or below indicated a slightly pessimistic view of life events on the part of the parent. One mother scored below 13 on the both the pre- and post-test measures of the *LOT*. All other parents scored 23 or above on the post-test outcomes of the *LOT*. A score of 23 or higher indicated an above average level of optimism towards life events. Three parents showed an increase in their scores from the pre-test measure, and one showed a slight decrease.

The *F-COPES* was created to identify the problem solving skills used by parents when they respond to problems or difficulties (McCubbin, Olsen, & Larsen, 1981, p. 135). On the *Passive Appraisal* subscale, all participants had pre- and post-test scores above the normal range established for this instrument. These above average scores indicated that these parents actively dealt with the difficult situations they face, perhaps more so than did parents in the general population. The high scores on this subscale indicated that the parents were confidence in their ability to influence the outcomes of family or situational events (McCubbin et al., 1981). The post-test scores of all the participants were higher than their corresponding pre-test score.

The *Reframing* subscale on the *F-COPES* provided an indication of the family's perception of change (McCubbin & Patterson, 1981). Respondents who scored between 25 and 35 on this scale view change with an average amount of optimism. Scores above 35 indicated that the respondents have an above average ability to define situations in a positive manner in order to make them more manageable. Three parents scored within the normal range on this subscale in the pre-test data and the scores of the fourth parent were in the above average range. The post-test scores of all research participants fell within the normal range for this subscale. Two parents showed a decrease in their score from the pre-test to post-test time period, and two parents exhibited an increase in their score on this subscale.

All mothers reported at least average levels of optimism, active coping strategies and ability to reframe difficult situations in a positive manner.

Scores for most parents improved in these subscales, so it could be said that parents did tend to view life events more positively after completing the post-test measures. There is no way to determine whether or not this increase in optimism is a result of participation in this study.

Research Question #6:

> Did the research participants see a clear connection between the family assessment data and the information they wrote down on the IFSP form?

From responses to the Final Questionnaire, it appeared that most parents (three out of four) were **Not Sure** that they saw a clear connection between the family assessment data and providing information for the completion of an IFSP. Only one parent indicated that she did see a clear connection between these two components. Two of the research participants did, however, indicate that they felt that the Family Profile accurately reflected their family's concerns. One parent said she was **Not Sure** about and one parent **Disagreed** with the statement "I feel the family profile accurately reflected our family's concerns." (Question #5 on the Final Questionnaire). One mother commented "At that point in time I agree, but life is an ongoing process...things change as time goes on." She seemed to indicate that the pre-test measures were accurate at the time they were completed, but some of their family situations had changed by the time the Family Profile was developed for them. Another parent stated "..there are many areas we need to concentrate on. This helped us recognize them."

Research Question #7:

> Were there any changes in the needs identified in the assessment measures and those written down by participants on the IFSP form?

This question was intended to discover whether or not parents used the information from the assessment measures to directly identify their own resources, needs, and potential goals. The discussion of this research question will involve outlining the strengths and needs identified in the Summary, and comparing these to the items the parents recorded on the IFSP Form.

The strengths listed for each family on the Summary were derived from the completion of the *CHIP, F-COPES, SSI, FIRM* and *FAM*. These strengths included: maintenance of family integration, cooperation and communication; maintenance of family support, esteem and stability; medical consultation and communication; optimistic outlook on life events; ability to redefine situations to make them more manageable; the level of support parents receive from the sources on the *SSI*; sense of family self esteem and communication; financial resources; and a shared pattern of coping strategies.

The strengths of the family listed by parents on the IFSP Form included: good family communication; close family; supportive work environments (they allow time off to keep appointments); financial security; suitable access to community resources; spending time together as a family; ability to take time away from the children; practical support from interventionists; quality care from health professionals in town and in the city; ability to help children learn at home; support from family members and the ability to travel to access resources in and out of their neighbourhood. None of the parents stated that their optimism, ability to actively deal with or redefine events were strengths, nor did they indicate that a shared pattern of coping strategies with their spouse was a strength for their family system.

The "Needs" listed by parents were phrased as goals they would like to work on, and were not based on the needs listed in the Summary. For example, one mother identified a need to increase the amount of communication between she and her husband, even though the Summary listed a "shared pattern of coping strategies" and "high levels of family communication" as strengths in this family system. Information in the Summary for another parent indicated that some areas associated with parent/ child interactions seemed to be sources of stress for the respondent. The mother however, listed spending time with her children as a strength on the IFSP Form. There did appear to be changes in the needs identified in the assessment measures, and those written down by participants on the IFSP Forms.

Research Question #8:

> What suggestions do parents have regarding improving the development of an IFSP.

Only two parents provided comments to this question. One mother stated that she thought the process implemented in this study "..would be very time consuming to do for each family, and very temporary as things change. Maybe could be used for families having difficulties." The other mother commented that she felt it was important for interventionists to help family members recognize their strengths. These comments will be dealt with more fully in the following chapter.

Conclusion

The results of this study have been described using quantitative measures (assessment scores) and information contained on the IFSP Forms, Summary document, and contact notes made following each home visit. An interpretation of these results will be provided in the following Discussion chapter.

CHAPTER V - DISCUSSION

The results obtained through the formal assessment measures and the Final Questionnaire are interpreted in this chapter. These data revealed some weaknesses of the system piloted in the study, and some suggestions are offered for improving this process. These suggestions lead to a discussion of the limitations of this study and this is followed by a list of recommendations for future research on this topic. Finally, the issues associated with implementing the IFSP process into local early childhood special education programs (ECSEPs) will be explored and connected to the need for increased levels of interagency collaboration.

Interpretation of the Results

The fact that most parents found the assessment measures helpful reinforces statements in the literature regarding ways that formal assessments play an important role in helping family members identify their needs, resources, and goals. Sexton et al. (1991) stated that parents felt comfortable sharing information through surveys and were able to understand the components of them far better than was predicted by interventionists. The comments offered by parents in the present study ("It was a boost to find out we were doing 'OK' according to someone else." and "Very interesting to see how closely my husband and I matched up.") could be interpreted to mean that the assessments which focussed on strengths and coping strategies were the most helpful to parents.

The answer to the question of whether or not the stress level of the participants was reduced throughout the course of the study is not clear. Although the parents did indicate, in their responses on the Final Questionnaire, that they felt their level of stress was reduced, the data from the assessments revealed a variety of results. (An increase in score over the pre-test results for three families on the *FSI* and for two families on the *PSI*.) One possible explanation for this increase in the amount of stress identified by the measures could be that parents of children with handicaps typically have elevated scores in the *Child Characteristics Domain* of the *PSI*. This does not indicate dysfunction in the family. It is, however, a reflection of the extra demands associated with a child with special needs (Loyd & Abidin, 1985).

An increase in the stress level reported on the formal measures was not perceived by parents according to their answers to question #6 on the Final Questionnaire. Many other studies have reported increased levels of stress in well functioning families of children with handicaps (e.g. Beckman, 1983; Berdie & Selig, 1981; Dyson, 1991; Hanson & Hanline, 1990; McCubbin, 1989; Minnes et al., 1989; Reddon, 1989; Zeitlin et al., 1987). These studies have also stated that the level of stress is not a reliable predictor of family adaptation (Dyson, 1991).

The strategies that family members use to cope with stressors, evaluate the meaning of life events, and implement personal and system resources provide much more information about the overall adaptation of the family system than does a measure of the stress level (McCubbin & Patterson, 1981). It may now be time for interventionists to assume that families of children with disabilities are functioning with high levels of stress, and not spend time identifying, analyzing or assessing it. Instead, it may be more helpful for interventionists to identify those strengths and resources family members use to assist them in handling the overwhelming events that occur so frequently in their lives (Dyson, 1991).

Some of the participants offered comments regarding improving the process for developing IFSPs. One mother stated that the process was very time consuming and mentioned that it should perhaps only be used for families having difficulties. This process did involve a great deal of time on behalf of the participants and the researcher. Each assessment package took at least 1 hour for a parent to complete, approximately 45 minutes for the researcher to score, about 1 hour for the researcher to compile the Family Profile and Summary, and 60 -90 minutes to fully explain the results to and answer questions from family members. The total time to complete, score and interpret the assessment package is approximately 4 hours. Additional time would be required to establish individual and family goals for each program participant. It may not be possible for many interventionists or parents to spend this much time on any assessment process.

Perhaps interventionists could explain the intent of all of the assessment measures to parents, then ask them which ones they would like to complete. Since one parent stated that it was important to "help families recognize and implement (their strengths)", it may be appropriate to invite parents to complete the *F-COPES*, *CHIP*, *SSI*, *LOT* and *FIRM*. These measures focus on family strengths, resources and coping strategies, and may provide family members with information that they could easily accept and incorporate into an IFSP.

Another parent commented that the assessment measures reflected their family's concerns at the time, but stated that "...things change as time goes on". This comment highlighted the need for a flexible approach to creating an IFSP that would be responsive to the changing needs of families over time (Deal et al., 1989). Perhaps a process that was less time consuming than the one piloted in this project would be perceived as more flexible.

Throughout this process, there may have been some confusion in the presentation of the assessment information as it pertained to completing the IFSP form. Three of the parents said they were **Not Sure** they saw a clear connection between the assessment data and information on the IFSP form. Two possible reasons may exist for this situation.

One possible reason for this lack of consistency may be that the terminology used in the Summary was taken from the assessment measures, and was not the vocabulary generally used in daily conversation. For example, under section **"c" "Problem Solving and Coping"** in the Summary, the coping strategies were listed as: (a) maintenance of family integration, cooperation, and communication; (b) maintenance of family support, esteem, and stability; and (c) medical consultation and communication. It may have been more helpful to phrase these strategies as: (a) strong relationships among family members and a positive outlook on family life; (b) relationships with family and friends that help build feelings of self worth and help to better manage tensions and pressures; and (c) helpful relationships with health care professionals and other parents of children with special needs. Overall, the terminology used in the Summary may need to be oriented less towards the assessment measures and more towards the vocabulary used by parents in their daily conversations with friends and family members. Interventionists must take care to accurately paraphrase the purpose and meaning of the assessment measure when translating the terms into a more common vocabulary (Able-Boone et al., 1992; Cranwell & Miller, 1987).

A second aspect of the process which may help family members incorporate assessment information onto the IFSP Form (Appendix G) could be to revise the form so that it specifically refers to the information located on the Family Profile. Interventionists must be careful, however, to allow parents to identify their own strengths, needs and goals and not have them feel compelled to commit to the information contained on the Family Summary. A sample of the proposed Revised IFSP Form is located in Appendix I.

In summary, the suggested revisions to the procedures used in this study are:

1. Focus on identifying the coping strategies, personal and family system resources, and situational appraisal skills of family members.

2. Provide frequent contact with family members to ensure that the Family Profile continues to be an accurate representation of family strengths, needs, and goals.

3. Clearly explain the purpose and intent of each assessment measure. Offer parents choices of assessments they wish to complete. Continue to invite family members to re-write assessment measures they see fit.

4. Use terminology common to family members. It may not be helpful to use the terminology associated with the assessment measures, even if a glossary is provided.

5. Use the Revised IFSP Form as it more closely parallels and refers to the Family Profile and Summary than did the original form.

Limitations of the Study

The low number of participants in this study limits the ability of researchers to generalize these results to wider populations. This small sample size allowed the researcher to have time to effectively meet with the parents and discuss the details of their strengths, needs and goals. The continuity of the visits took priority over a larger sample size.

A second aspect of the study that may limit the ability to generalize the results is the fact that the participants must have completed the Redington (1992) study in order to qualify for the current study. This selection process did not allow for a representative sample of families to be chosen for participation in this study.

Third, the IFSP process investigated in this study was parallel to other individualized plans the family members had completed in the ECSEPs in which their children were involved. This confounding effect may have affected the practicality of the goals set by parents. Since only two parents **Agreed** that they were able to achieve the goals listed on the IFSP, it is difficult to assess the true usefulness of this process in terms of helping families achieve their goals. A more accurate measure of this process may occur if it is implemented within the structure of an ECSEP, at the beginning of the school year.

A fourth limitation of the study involves the fact that only the mothers participated in visits and completed the final assessment forms. This did not satisfy the basic principles associated with family focussed intervention and systems theory, two key components of this process. Parents were given the choice of when they wanted the visits, and who they wished to have present at that time. If mothers chose a time that did not allow for the father to be present, the researcher did not question the decision. Although involving all family members in the identification of strengths, needs, and goals is a valuable practice, this may be difficult to arrange in some family situations. Some structural barriers such as work and child care schedules, past and present role definitions for each parent, and preferences of each parent regarding their own level of participation may need to be addressed in order to more fully include all family members in the development of an IFSP.

Recommendations for Future Research

The development of IFSPs is a process that seems quite new to ECSEPs in Alberta. Many possibilities exist to explore and refine this topic further. The next step in discovering practical methods of relating family assessments to goal setting may be to pilot this process (incorporating the suggested revisions) into the structure of a well established ECSEP. A cooperating program may select a few families for whom this procedure could be piloted and evaluated. Criteria for evaluation could include assessing whether or not family members accomplished the family goals listed in the IFSP and identifying the assessment measures family members found most helpful when setting these goals. It may also be of interest to discover what differences (if any) exist in the level of satisfaction among parents who complete an IFSP experience compared to those who complete the traditional Individualized Education / Program Plan (IEP or IPP).

Applying the IFSP Process in Local Programs.

The use of IFSPs in early childhood special education programs in Alberta has not been well documented and there is little evidence that IFSPs are used in these programs. One reason for their lack of use could be that ECSEPs are mandated to develop an IEP or IPP for each child, not an IFSP (Alberta Education Response Centre, 1992). There are neither the funds nor the authority for ECSEPs to provide family related services that go beyond tradition educational guidelines (e.g., counselling, supplemental income, nutrition information, respite services). Most of the community agencies offering these services take referrals only from the parents themselves. The delivery of these services cannot be monitored or even initiated by interventionists. The role of the interventionist is limited to providing parents with information on these community resources. Since these family needs must be met by agencies outside the ECSEP, it is not currently feasible for educators to transform these needs into goals on an IFSP.

The current social and political climate in Alberta regarding meeting the needs of families in educational settings is summarized by this researcher in the following quotes.

> 1. "Parents should participate in decisions involving formal assessment and diagnosis of their child, and in the selection and arrangements for any special services that are needed. They should be part of any decisions that are made as a result of a review of their child's progress and in the development of the IPP." (Alberta Education Response Centre, 1992, p.1-3).

> 2. "Government policies and programs will seek to support and strengthen families and decrease the potential for family crisis" (Premier's Council in Support of Alberta Families, 1992, p. 20).
>
> 3. "Looking at the financial situation we're in, I find it difficult to reconcile going beyond our mandate of education." (Edmonton Public Schools, 1993, p.3).

These quotes can be compiled and interpreted to mean that the role of parent partnership as outlined to education program administrators is limited to that of participating in decisions. This is a drastic difference from parents taking the leadership role of directing early intervention services that is outlined in the literature (Bailey & Simeonsson, 1988; Dunst et al., 1988). It is important to mention, however, that many ECSEPs do incorporate the principles of family focussed intervention though they are not required through laws or funding guidelines to do so. The agencies involved with the families who participated in this study seemed to provide family focussed services and the parents stated their appreciation of these practices.

Second, although the policy statement of the provincial government proclaims that it will "seek to support and strengthen families", the individual departments funded by the government are not likely to embrace this statement until they receive the mandate (i.e., funding and responsibility) to do so. Currently, the incentive for administrators of ECSEPs to develop IFSPs and implement a family focussed model of service delivery is the knowledge that these practices will maximize the intervention their programs offer (Raver & Kilgo, 1991). There is philosophical support, but no financial nor structural encouragement by the funding agencies for ECSEPs to develop IFSPs for the families involved in their programs. School boards are eager to ensure that the education of students does not suffer because of education dollars going to services which they believe should be provided through social or health programs.

The preceding statements illuminate the need to promote more interagency collaboration throughout the many government departments that meet the needs of children and their families. Peterson and Mantle (1983) state that the possible benefits of interagency collaboration include the expansion and improved accessibility of services, normalized service delivery through working with community agencies, and the promotion of community wide planning instead of a scattered approach to the delivery of services. Obstacles that may interfere with the processes involved in establishing interagency collaboration can be listed as: a lack of experience among professionals in the techniques of interagency cooperation; the lack of a central base of resource information; and an inconsistent approach to the delivery of information to family members (Lowenthal, 1992). Perhaps with time, training and commitment from government agencies to structurally and financially support interagency collaboration, IFSPs will become integral to the delivery of services to the families of children with special needs.

Conclusion

This study was able to incorporate many of the aspects of a systems based, family focussed approach when developing IFSPs with families of children who have special needs. Although the sample size was small, there was sufficient feedback to evaluate this process and suggest some improvements to the process that may lead to the development of a refined IFSP procedure. It is hoped that this information obtained through this study will be helpful to researchers and interventionists who may wish to implement this process in the future.

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APPENDIX A

Final Questionnaire

IFSP PILOT

FINAL QUESTIONNAIRE

INSTRUCTIONS To complete this questionnaire you are asked to research statement one at a time. Then, circle the answer which best describes your feelings. While you may not find an answer which comes closest to describing how you feel. Please circle how much you agree or disagree with the following statements. If you are unsure, you should circle "Not Sure".

1. **I found the information from the assessments (Family Profile) helpful.**

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

2. **I do not think that the information on the assessments indicated our family's strengths.**

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

3. I feel less stress now that I have participated in this project.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

4. I feel more confident when talking with people who work with my child since participating in this study.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

5. I feel the family profile accurately reflected our family's concerns.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

6. I feel more stress now that I have participated in this project.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

7. I see a clear connection between the family assessment data and the information written on the Individual Family Service Plan.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

8. I was able to reach most of the goals listed on the Individual Family Service Plan.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

PLEASE COMMENT:

9. What suggestions do you have regarding improving the development and implementation of an IFSP?

____

____

____

____

10. What suggestions do you have regarding the implementation of an Individual Family Service Plan?

____

____

____

____

APPENDIX B

Protocol for Home Visits

PROTOCOL FOR INTRODUCTORY HOME VISIT(S)

Guiding Principles for the visit:

1. To promote positive child, parent and family functioning, base intervention efforts on family identified needs, aspirations, personal projects and priorities.

2. To enhance successful efforts toward meeting needs, use existing family functioning style (strengths and capabilities) as a basis for promoting the family's ability to mobilize resources.

3. To insure the availability of resources for meeting needs, placing major emphasis upon strengthening the family's personal social network as well as promoting utilization of untapped but potential sources of informal aid and assistance.

4. To enhance a family's ability to become more self-sustaining with respect to meeting its needs, employ helping behaviours that promote the family's acquisition and use of competencies and skills necessary to mobilize and secure resources.

(Adapted from Dunst et al., 1988 p. 53)

Purpose of the visit:
1. To meet parents
2. To discuss any issues regarding the research project (e.g. voluntary participation, right to withdraw, confidentiality).
3. To review family assessment information as summarized on the Family Profile.
4. To introduce the IFSP form and invite parents to complete this if they wish.

PROTOCOL FOR INTRODUCTORY HOME VISIT(S) (con't)

Activities:

Introduction: Explain purpose of the visit (listed above)
Confirm informed consent to participate in the study.

Review information on the Family Profile:
Present completed Family Profile
Refer to these results as "a picture of your family"
Encourage family members to "make sure the picture looks right"
Discuss reactions and responses to the information in order to obtain a completely accurate representation of the family.

Completing the IFSP Form:
Ask family members what goals they would like to work towards, and write these down.
Ask family members if these could be goals on the IFSP.
Fill in IFSP form.

Concluding Activities:
Express appreciation and recognition of family members' contributions.

(Adapted from Olson & Kwiatkowski, 1992, pp. 64-65)

PROTOCOL FOR FOLLOW-UP HOME VISITS

Guiding Principles for the visit:

1. To promote positive child, parent and family functioning, base intervention efforts on family identified needs, aspirations, personal projects and priorities.

2. To enhance successful efforts toward meeting needs, use existing family functioning style (strengths and capabilities) as a basis for promoting the family's ability to mobilize resources.

3. To insure the availability of resources for meeting needs, placing major emphasis upon strengthening the family's personal social network as well as promoting utilization of untapped but potential sources of informal aid and assistance.

4. To enhance a family's ability to become more self-sustaining with respect to meeting its needs, employ helping behaviours that promote the family's acquisition and use of competencies and skills necessary to mobilize and secure resources.
   (Dunst et al., 1988 p. 53)

Purpose of the visit:

1. To ask parents how the goals listed on their IFSP are fitting their current needs.
2. To discuss possible adaptations to the IFSP if indicated by the family members.
3. To remind participants of their right to withdraw from participation at any time.
4. Ask family members how they feel about the goals listed on the IFSP and any progress towards achieving them.
5. Clarify any questions regarding the IFSP form or process.

Activities:

1. Explain purpose of the visits (listed above).
2. To discuss possible adaptations to the IFSP if indicated by the family members.
3. To remind participants of their right to withdraw from participation at any time.
4. Ask family members how they feel about the goals listed on the IFSP and any progress towards achieving them.
5. Complete follow-up form on the next page.

FOLLOW-UP FORM

Family Code: ________________ Date: ____________________

Family concerns, priorities, resources
Family progress/changes
Suggested focus for intervention

(Adapted from Olson & Kwiatkowski, 1992, p. 66).

PROTOCOL FOR FINAL HOME VISIT

Guiding Principles for the visit:

1. To promote positive child, parent and family functioning, base intervention efforts on family identified needs, aspirations, personal projects and priorities.

2. To enhance successful efforts toward meeting needs, use existing family functioning style (strengths and capabilities) as a basis for promoting the family's ability to mobilize resources.

3. To insure the availability of resources for meeting needs, placing major emphasis upon strengthening the family's personal social network as well as promoting utilization of untapped but potential sources of informal aid and assistance.

4. To enhance a family's ability to become more self-sustaining with respect to meeting its needs, employ helping behaviours that promote the family's acquisition and use of competencies and skills necessary to mobilize and secure resources.

(Adapted from Dunst et al., 1988 p. 53)

Purpose of the visit:

1. To invite parents to complete family assessment measures and questionnaire.
2. To remind parents of their right to withdraw from participation in this project at any time.
3. To ask parents if they have any questions or would like further follow-up to this process.
4. To thank parents for their contribution to this study.

PROTOCOL FOR FINAL HOME VISIT (con't)

Activities:

1. Invite parents to complete family assessment measures. Offer them choices of:
   A) Completing the measures at their home.
      i) With me reading the questions/statements and the parents responding (with my view of their response sheet obscured).
      ii) With parents reading the questions/statements independently.

   B) Complete the measures in their own time and return them to me in the self addressed stamped envelope.

2. Invite parents to complete questionnaire. Offer them choices of:
   A) Completing the questionnaire at their home.
      i) With me reading the questions/statements and the parents responding (with my view of their response sheet obscured).
      ii) With parents reading the questions/statements independently.
   B) Complete the questionnaire in their own time and return them to me in the self addressed stamped envelope.

3. Remind parents of their right to withdraw from participation in this project at any time.

4. Ask parents if they have any questions or would like further follow-up to this process.

5. Thank parents for their contribution to this study.

APPENDIX C

Overview of Proposal for Cooperating Agency

OUTLINE OF THESIS PROPOSAL "PILOTING A PROCESS FOR DEVELOPING AN INDIVIDUALIZED FAMILY SERVICE PLAN"

Overview of the Process:

1. Potential research participants will be selected from those who took part in the Redington study.
   Reason: To follow up on an important process started by Caroline.
   To utilize assessment data from these families in a practical way.

2. Potential participants will be contacted by me, will receive a copy of the consent form and will be invited to ask any questions.

3. Data from family assessments completed in the Redington study will be summarized onto the Family Profile sheet for those families who agree to participate in this study.

4. This summary of information will be presented to research participants at the first home visit.

5. Parents will be asked to confirm that this profile still portrays an accurate "picture" of their family. Family members will be invited to add new information to this Profile as they see fit.

6. Family members will be asked to use this family assessment information to develop goals to be included on the IFSP form.

7. The IFSP form will be filled out.

8. I will phone or visit families two times after the IFSP form has been completed. The purpose of this is to: answer any questions about the process; ask parents how they feel about the IFSP process and remind parents of their right to withdraw from this project at any time.

9. During the final home visit, parents will be asked to complete the following family assessment measures: Family Stressors Index (FSI); Parenting Stress Index (PSI); Family Inventory of Resources for Management (FIRM); Life Orientation Test (LOT); Coping and Health Inventory for Parents (CHIP) and the Family Assessment Measure III (FAM III). They will also be asked to complete a questionnaire developed specifically for this project.

Benefits of an IFSP:

1. Assist parents to identify those priorities and activities to which they wish to devote their time and energy.

2. Assist interventionists to best utilize their time by focussing on those goals that have been identified as priorities by family members.

3. Incorporate the principles and practices of a family centred and family guided approach to intervention.

4. The use of IFSPs is widely supported in the literature.

Principles and Frameworks to be incorporated in this study:

1. Family centred approach. (Bailey et al., Dunst et al., Olson & Kwiatkowski).

2. Family Systems Theory

3. All activities will strive to empower and enable family members to meet their needs in ways that best fit with their family structure.

4. The T-Double ABCX model of family functioning (McCubbin & Patterson).

Ethical considerations:

1. Confidentiality of information. Coded names, master list locked away, information from family members will only be discussed with my advisors.

2. Parents will be reminded throughout the course of this project of their right to withdraw from participation in this study at any time.

Questions to ask of agency staff.

How would you like to be involved?

1. By contributing input into the selection of potential research participants?
2. By accompanying me on some (all) of the visits?
3. By continuing the work you are currently doing with families to help them achieve the goals listed on their IFSP?
4. By providing follow-up visits to these families after this study has been completed?
5. What type of ongoing communication would you like to have with me throughout the course of this study?
   (Clarify number of contacts, time lines, contact person)
6. What type of contact would you like to have with my thesis advisors throughout the course of this study?
7. Other?

Are there adaptations I could make to this process that would make it more practical/effective for you and the families that you serve?

How may I be of help to you as you meet the needs of families in your community?

What questions for you have for me?

APPENDIX D

Consent Form and Letter of Introduction

CONSENT FORM
FOR RESEARCH ON DEVELOPING AN INDIVIDUALIZED FAMILY SERVICE PLAN

I understand that the purpose of this study is to evaluate a process for creating an Individualized Family Service Plan for me and for my child.

I understand that I will be asked to have four visits from the researcher over a four month period. Each of the visits will last for approximately one hour.

I understand that I will be asked to complete a variety of family assessment measures and one questionnaire at the end of this study.

I understand that I have the right to stop taking part in this research project at any time.

I understand that all information will be kept confidential. No information will be passed on to anyone else without my specific permission.

I understand that I can ask questions to the researcher and/or her thesis advisors at anytime. These people are:

Cathy Martin	988-6639 (res)	439-0868 (bus)
Dr. Gerard Kysela	(Thesis Co-Advisor)	492-5026
Dr. Linda McDonald	(Thesis Co-Advisor)	492-2198

By signing this form, I agree to participate in the research study outlined above. I have been informed of the purpose and understand the procedures involved in this study. I understand that I may withdraw from participation in this study at any time.

Signature of Participant ________________ Date ________________

Witness ________________ Date ________________

IFSP PILOT

Date

Dear Parents

Last year, you participated in a study done by Caroline Redington in which you completed several family questionnaires. This letter is to invite you to take part in a new study that will evaluate a way of creating an Individualized Family Service Plan (IFSP) using the information gathered in Caroline's study.

Your participation in this project is entirely up to you, and you would be free to stop your involvement in it at any time. All information gathered and used in this study will be held in the strictest confidence and your name will not be written on any document used for or created in this project.

If you choose to participate in this study, you would receive four home visits over a seven month period of time. These visits would be arranged at your convenience. At the end of this project, you would be asked to complete some of the same assessments used in Caroline's study and a short open ended questionnaire.

If you would like, I would be happy to work closely with the professionals who are already providing services to you and your family.

Please feel free to phone me at 439-0868 (work) or 988-6639 (home) if you have any questions regarding this project.

If you agree to participate in this project, arrangements will be made to meet with you and explain aspects of the project.

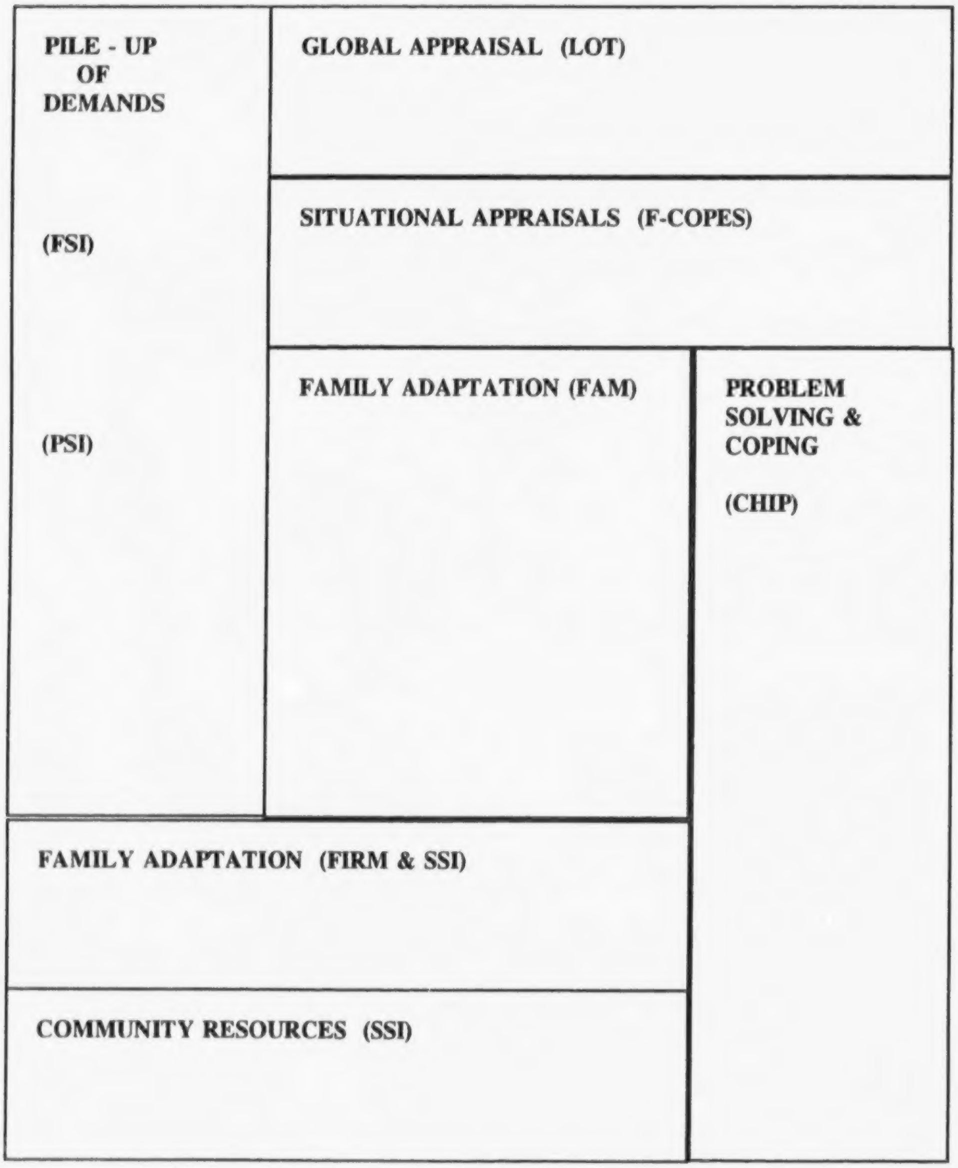
Thank you for taking the time to consider the information in this letter. If you have any questions, please feel free to call me at any time. I'm looking forward to working together with you.

Sincerely,
Cathy Martin (988-6639)
Graduate Student, University of Alberta

APPENDIX E

Family Profile and Summary Sheets

FAMILY PROFILE DIAGRAM (By Maureen Nelson)


PILE - UP
OF
DEMANDS
(FSI)
(PSI)
GLOBAL APPRAISAL (LOT)
SITUATIONAL APPRAISALS (F-COPES)
FAMILY ADAPTATION (FAM)
PROBLEM
SOLVING &
COPING
(CHIP)
FAMILY ADAPTATION (FIRM & SSI)
COMMUNITY RESOURCES (SSI)

IFSP PILOT

SUMMARY

GENERAL INFORMATION

Parent(s):

Child :

Address:

Phone:

ASSESSMENT INFORMATION

Referral Source:

Assessment Date: / /

Conference Date:

FAMILY PROFILE SUMMARY

I	**Family Adaptation**	Your responses to the *Family Assessment Measure* suggest an overall ___level of family adaptation. Both of you indicated similar views of your family's _____. These areas are also positive strengths for you as a couple. There were some discrepancies between your perceptions of family functioning related to _______.
II	**Pile-Up of Demands**	From your responses to the *Family Stressors Index* you appeared to be experiencing (the typical level / a number) demands related to life events and changes. On the *Parent Stress Index* you both indicated (a normal level of stress, several concerns) related to your perceptions of (child's name) (*adaptability, acceptability, demandingness, mood, distractibility, and the reinforcement you receive as parents*). (Parent name) however, perceived (child's name) (*adaptability, acceptability, demandingness, mood, distractibility, and the reinforcement he/she receives as a parent*) as being a source of concern.

III. Family Capabilities

a. Appraisals On the *Life Orientation Test* you indicated an optimistic view toward the outcomes of life events. Your responses on the *F - Copes* indicate that you seem to take a positive view of difficult situations, to face them directly and to have confidence in your ability to positively alter the outcomes.

b. Resources Your responses to the *Family Inventory of Resources for Management* and to the *Social Support Inventory* showed that you receive adequate support from (*other family members, relatives, friends, community groups, community services, and professionals*).

(As a couple you / parent name) indicated family strengths related to your family's sense of (*esteem and communication, mastery and health, and adequate financial resources*).

c. **Problem Solving and Coping** Your responses on the *Coping and Health Inventory for Parents* showed that you have typical repertoire of coping strategies. These strategies include the following:

- maintenance of family integration, cooperation and communication
- maintenance of family support, esteem and stability
- medical consultation and communication.

Parent comments regarding family capabilities and strengths
(i.e. additional family strengths generated by the family)

Overview of Family Adaptation

Your responses to the assessments comprising the Family Profile indicated that your family has achieved a (positive level of / concerns regarding your) of overall family adaptation. A balance and fit (there may not yet be a fit) among the demands your family faces and your family's capabilities to meet these demands. Some of the capabilities, strengths and resources that have contributed to your positive adaptation include the following:

1. (Your optimistic outlook on life events and outcomes, your positive appraisals of specific difficult situations).
2. (You also appeared to have an adequate level of support from [other family members, relatives, friends, community groups and professional services]).
3. (Other family capabilities include your [sense of family esteem, family communication, adequate financial resources]) (as well as your problem solving and coping strategies.)

Parent Comments and Questions:

____

____

____

____

____

____

____

Priorities

What are your priorities for the development of your Individualized Family Service Plan (IFSP).

APPENDIX F

Glossary of Terms used for Assessment Measures

Assessment Glossary

***FAMILY ASSESSMENT MEASURE* (FAM)**

This questionnaire measures the family's efforts to regain balance after major difficulties or crisis situations. It contains a list of 50 statements and you were asked to answer by circling a number from 1 - 5, with 5 being that you "strongly disagree" with the statement and 1 being that you "strongly agree" with the statement. This questionnaire is divided into the following seven areas (subscales).

1. **Task Accomplishment.**
   This scale looks at the way basic tasks are being met in the family and whether these tasks are shared by family members. Examples are:
   "We never let things pile up until they are more than we can handle."
   "When things aren't going well it takes too long to work them out."

2. **Role Performance.**
   This scale measures how family members understand what is being expected of them and if they agree to do their share of the work to get things done. Examples are:
   "We agree about who should do what in our family."
   "We can't rely on family members to do their part."

3. **Communication.**
   This scale looks at whether or not family members are getting enough information to understand what is going on and if the messages are clear and direct. Examples are:
   "We argue about who said what in our family."
   "We take time to listen to each other."

4. **Affective Expression.**
   This scale looks at family members' ways of expressing how they feel about general things and explores whether this expression is done in an appropriate way.
   Examples are:
   "I can't let my family know what is bothering me."
   "When someone is upset, we don't find out until much later."

5. **Affective Involvement.**
   This scale assesses the level of family members' concern for each other leading to feelings of security and mutual growth. Examples are:
   "We really don't trust each other."
   "My family tries to run my life."

6. **Control.**
This scale looks at the extent to which those people who have the most influence within the family encourage stable family life, and if family routines are predictable yet flexible. Examples are:
"We hardly ever do what is expected of us without being told."
"Punishments are fair in our family."

7. **Values and Norms.**
This scale checks to see if values are consistent between the family and community, and whether the family members are comfortable with the way the family operates. Examples are:
"It's hard to tell what the rules are in our family."
"We have the same views on what is right and wrong."

SCORING Average scores typically range from 40-60 in each subscale. Scores above 60 may indicate a degree of difficulty in dealing with the issues associated with that subscale.

PARENTING STRESS INDEX *(PSI)*

This index measures the amount of stress that may exist in a parent/child relationship. It contains a list of 50 questions that you were asked to answer by circling a number from 1 - 5, with 5 being that you "strongly agree" with the statement and 1 being that you "strongly disagree" with the statement. The index is broken down into 6 areas (subscales).

1. **Adaptability.**
   This scale looks at the way your child adjusts to changes in her/his environment or routine. Examples are:
   "Leaving my child with a baby sitter is usually a problem."
   "It takes a long time and it is very hard for my child to get used to new things."

2. **Acceptability.**
   This scale looks at how closely your child's appearance, behaviour and development match your expectations of her/him. Examples are:
   "My child doesn't seem to smile as much as other children."
   "My child does a few things that bother me a great deal."

3. **Child Demandingness.**
   This scale looks at how much of your time and energy is spent on meeting the needs of your child. Examples are:
   "My child is always hanging on to me."
   "My child seems to be much harder to care for than most."

4. **Child Mood.**
   This scale looks at whether or not your child seems happy most of the time or cries a lot. Examples are:
   "My child generally wakes up in a bad mood."
   "When playing, my child doesn't often giggle or laugh."

5. **Child Distractibility/Hyperactivity.**
   This scale looks at how active your child is throughout the day, how long s/he can attend to a specific task and how well s/he can follow through when you ask her/him to do something. Examples are:
   "My child is so active that it exhausts me."
   "My child can easily be distracted from wanting something."

6. **Parent Reinforcement.**
   This section looks at how much feedback you get when you interact with your child. Examples are:
   "Most times, I feel my child likes me and wants to be close to me."
   "My child smiles at me much less than expected."

FAMILY STRESSORS INDEX *(FSI)*

This index identifies how many stressful life events were experienced by your family within one year. 10 events that could be stressful to individuals or families (e.g. moving, returning to work, the birth of a child, etc.) were listed on the index. You were asked to answer YES or NO to each question. Points were given for each YES response. The higher the score, the more stressful were the events experienced by your family.

LIFE ORIENTATION TEST *(LOT)*

This test looks at the meaning a family attaches to difficult situations.

Examples are: "Every cloud has a silver lining."
"I am optimistic about my future."

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES *(F-COPES)*

This scale looks at how members view the family in relationship to the community, and how they view their life situations. The F-COPES is divided into the following two areas (subscales):

1. **Passive Appraisals.**
   This scale looks at the active or passive behaviours family members use to deal with life situations. Examples are:
   "We know luck plays a big part in how well we are able to solve family problems."
   "We believe if we wait long enough, the problem will go away."

2. **Reframing Family Problems.**
   This scale looks at how the family redefines difficult situations in a positive manner to make them more manageable. Examples are:
   "We have the power to solve major problems."
   "We face our problems 'head on' and try to get a solution right away."

SOCIAL SUPPORT INDEX *(SSI)*

This index looks at how much support you get from family, relatives, friends, books and other resources. The types of support include: emotional (feeling loved or cared for); esteem (feeling valued and respected); network (having a sense of trust or security from the "give and take" of being involved with others); appraisal (feeling understood and getting help from others) and altruistic (feeling good about one's self when able to do things for others).

***FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT* (FIRM)**

This index was developed to identify the resources a family has when it deals with difficult situations, such as having a child with special needs. It contains a list of 62 statements and you were asked to rate how well each of the statements described your family situation on a scale of 1-4 (1 meaning that this statement did not describe your family at all, and 4 meaning that the statement described your family very well). The inventory is divided into 4 areas (subscales).

1. **Family Strengths I - Esteem and Communication**
   This section looks at the resources you have as a family in terms of the way you are able to communicate with, support and encourage each other, maintain an positive outlook and get respect from your family members and friends. Examples are:
   "Friends seem to enjoy coming to our house for visits."
   "We discuss our decisions with other family members before carrying them out."

2. **Family Strengths II - Mastery and Health**
   This section looks at how you view your ability to deal with events that occur within your family, the togetherness, cooperation and emotional support that exist within your family and your own physical and emotional health. Examples are:
   "We have to nag each other to get things done."
   "We seem to put off making decisions."

3. **Extended Family Social Support**
   This section looks at how much mutual support and help is given to and received from your relatives. Examples are:
   "We try to keep in touch with most of our relatives."
   "Our relatives do and say things to make us feel appreciated."

4. **Financial Well-Being**
   This section looks at how well you think you are able to meet the expenses involved with raising your family. Examples are:
   "We seem to have little or no problem paying our bills on time."
   "We feel we have enough money on hand to cover small unexpected expenses (under $100)."

COPING AND HEALTH INVENTORY FOR PARENTS **(CHIP)**

This scale identifies what parents find helpful as they go about all the tasks involved with raising a family when one family member has a short or long term illness or medical condition. It contains a list of 45 coping behaviours and you were asked to rate how helpful you found each of the behaviours to be on a scale of 1 - 4, with 1 meaning "not helpful" and 4 meaning "very helpful". The scale is broken down into three sections.

1. **Integration, Cooperation and Communication.**
   This section looks at behaviours that strengthen family life and relationships and that lead to a positive outlook on life with a child with special needs. Examples are:
   "Believing that my child is getting the best medical care possible."
   "Doing things with family relatives."

2. **Support, Esteem and Stability**
   This section looks at behaviours that help parents develop relationships with others, engage in activities that build feelings of self worth and manage pressures and tensions. Examples are:
   "Entertaining friends in our home."
   "Keeping myself in shape and well groomed."

3. **Medical Consultation and Communication**
   This section looks at ways in which parents can develop relationships with health care professionals and other parents of children with special needs. Examples are:
   "Talking with other parents in the same type of situation as myself."
   "Explaining our family situation to friends and neighbours do they will understand us."

APPENDIX G

IFSP Form

INDIVIDUALIZED FAMILY SERVICE PLAN

DATE: ______________________________

NAMES OF FAMILY MEMBERS

____

____

____

STRENGTHS AND RESOURCES WE HAVE AS A FAMILY ARE:

____

____

____

____

THINGS THAT WOULD BE HELPFUL TO US AS A FAMILY ARE:

____

____

____

____

____

IFSP PILOT

INDIVIDUALIZED FAMILY SERVICE PLAN

ONE THING WE WOULD FIND HELPFUL IS:

____

____

____

____

____

____

WE CAN GET THIS DONE BY DOING THE FOLLOWING:

____

____

____

____

____

____________________ HAS AGREED TO DO / ASSIST US WITH THIS TASK

THESE TASKS WILL BE DONE BY: ____________________________
(DATE)

APPENDIX H

Summary of Responses to the Final Questionnaire

FINAL QUESTIONNAIRE

1. I found the information from the Assessments (Family Profile) helpful.
   Disagree - There's too much other things going on right now.
   Agree - (2)
   Strongly Agree - It was a boost to find out that we are doing "OK" according to someone else. Also, to see the areas of weakness was helpful.
   Very interesting to see how closely my husband and I matched up. It made me see we really aren't opposed.

2. I do not think the information on the assessments indicated our family's strengths.
   Not Sure
   Disagree - (2)
   Strongly Disagree - I found it to be very accurate.

3. I feel less stress now that I have participated in this project.
   Disagree
   Not Sure (3) - But it is nice to know we are doing OK.

4. I feel more confident when talking with people who work with my child since participating in this project.
   Agree (2) -The school is helping a lot with my son.
   Not Sure (2) -But I am more aware of my strengths as I advocate for our child in relation to our whole family.

5. I feel the family profile accurately reflected our family's concerns.
   Disagree
   Not Sure - Since my husband did not contribute, I'm not sure of his concerns being as accurate as I feel they are.
   Agree (2) - Yes, there are many areas we need to concentrate on. This helped us recognize them.
   But things change as time goes on. At that point in time I agree, but life is an ongoing process.

6. I feel more stress now that I have participated in this project.
Disagree (4)- I may not write our difficulties down, but I am more aware of the thinking process.

7. I see a clear connection between the family assessment data and the information written in the Individual Family Service Plan.
Not Sure (3)
Agree

8. I was able to reach most of the goals listed on the Individual Family Service Plan.
Disagree
Not Sure
Agree - (2) Short Term goals - but we're there.
I became more aware of my goals.

9. What suggestions do you have regarding the improvement of the development of an IFSP?

Enjoyed the visits.
I think this would be very time consuming to do for each family, and very temporary as things seem to change. Maybe could be used for families having difficulties.

10. What suggestions do you have regarding the implementation of an Individual Family Service Plan?

Whether verbal or written to help families to recognize and implement.

APPENDIX I

Proposed Revised IFSP Form

Proposed Revised

INDIVIDUALIZED FAMILY SERVICE PLAN

DATE: ______________________________

NAMES OF FAMILY MEMBERS: ______________________________

______________________________ ______________________________

______________________________ ______________________________

______________________________ ______________________________

Strengths and Resources we Have as a Family:
(See Section III in the Family Summary)

Proposed Revised

INDIVIDUALIZED FAMILY SERVICE PLAN (Con't)

Goals we would like to set for our family are:

Strategies we use to help us Achieve Goals are:
(See Section III "c" on Family Summary)

Resources we can use to achieve these goals:
(See **Overview** Section on Family Summary)

Proposed Revised

INDIVIDUALIZED FAMILY SERVICE PLAN (con't)

Priority #	Outcome/ Issue / Task	People who can help With this task	Date of Completion

(Adapted from Olson & Kwiatkowski, 1992, p.135)